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August 2018



## RESEARCH REPORT

### Interviews with people at the end of life:

### End of Life Care for People with Alcohol and Drug Problems

"You were never believed  
and you were always made  
to feel like rubbish and it  
takes a lot to get past that  
and then start maybe  
putting a bit more trust in  
these people again."  
(Richard)

Authors:

Jo Ashby

Sam Wright

Sarah Galvani



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## Acknowledgements

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- We wish to thank the Big Lottery Fund for allocating funding for this research project.
- We are grateful to our interviewees for their courage and candour in talking about their own experiences and end of life support needs.
- This research would not have been possible without the enthusiasm, hard work and support from our colleagues at Trinity hospice (Blackpool), Voicebox Inc., Addiction Dependency Solutions, Aquarius, St John's hospice and St Catherine's hospice. Thank you all for your assistance, guidance and support throughout the study.

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## Terminology

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The terms below are used throughout this report to mean the following:

- **Ascites** - abnormal accumulation of fluid in the abdominal (peritoneal) cavity. The most common cause is cirrhosis of the liver.
- **COPD** - Chronic Obstructive Pulmonary Disease (for example: emphysema or chronic bronchitis). Typically a chronic, irreversible airway obstruction resulting in breathing difficulties.
- **End of Life** – refers to the last 12 months of a person's life (as far as that time period can be known).
- **Family** - refers to family members, close friends and carers – recognising that people with substance use difficulties often have fractured family relationships and may consider close friends to be more of a family to them than their blood relatives.
- **Palliative Care** – An holistic approach to maximising quality of life for people with terminal or complex illness where symptoms need to be controlled. Focusing on the prevention and alleviation of suffering, this includes not only pain management but also psychosocial and spiritual support for both the individual and their family, friends and carers.
- **Participant/Interviewee** – are used interchangeably to refer to the people taking part in our interviews.
- **Person with Experience (PWE)** - refers to the person with experience of substance use problems and end of life care needs.
- **Problematic substance use/Substance use difficulties** - A subjective definition which differentiates problematic alcohol or other drug use from recreational consumption. Problems may relate to physical or mental health issues, criminal justice involvement, financial and employment difficulties, family life, social support or housing, but may also include feelings of guilt or shame; secrecy about use; concerned family or friends; reliance on alcohol/drugs to relax or feel better; memory loss; or regularly using more than intended.
- **Substance Use** – refers to the use of alcohol or illicit drugs (those listed under the Misuse of Drugs Act 1971). For our research, we are focusing not only on drugs listed under the Misuse of Drugs Act 1971 (Schedule 2), but also use of New Psychoactive Substances (NPS) and misuse of prescription drugs. Use of tobacco is excluded.

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## Executive Summary

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1. The aim of this research was to document how people with (current or past) problematic substance use experience care at the end of their life and how they think that support could be improved.
2. This report presents findings from semi-structured interviews with 11 people with experience of alcohol or other drug difficulties and end of life care needs.
3. Our findings centre on five main themes: Anticipation of discrimination; Understanding the substance use and end of life care nexus; End of life communication; Adjusting to end of life and end of life care needs; and Managing the treatment and care experience.
4. **Anticipation of discrimination**  
Many of the people we interviewed anticipated discrimination from health and social care staff, largely because of poor past experiences with health care services. Consequently, feelings of mistrust resulted in late presentation to services for many. Some of those who did access health and social care services kept their substance use secret as one way of trying to minimise discrimination. Others tried to continue caring for themselves at home with little or no formal support, accessing emergency services when an acute health crisis made that necessary.
5. **Understanding the substance use and end of life care nexus**  
As well as dealing with complex health problems and the need to adjust psychologically to end of life, many of the participants talked about feeling deep regret, guilt and shame around their past behaviour. The interviews offered an insight into the complex challenges of having to come to terms with an end of life diagnosis and a past/present substance use issue. Rather than framing substance use dependency as a 'choice' and a self-inflicted behaviour that warrants little sympathy, through seeking background contextual information from each person, health and social care providers can gain a different insight that enable better relationships to form around trust, care and compassion.
6. **End of life communication**  
The majority of participants did not feel fully informed about their end of life condition. For people not in regular contact with health care services, there is a need to look at ways in which early conversations can take place in order to avoid unnecessary distress for the patient and their relatives. Having to communicate their prognosis to friends and family was an additional burden for many of the research participants that could be better supported.
7. **Adjusting to end of life and end of life care needs**  
For the people we interviewed, adjusting to end of life and accepting the need to receive formal healthcare meant having to balance a stigmatised substance using 'outsider identity' with a dependent 'insider identity' of needing care. This generated feelings of frustration and anxiety over a lack of control that impacted upon the provision/receipt of optimal care. Empathetic training for health professionals could help people with substance use problems by encouraging them to talk about their feelings and experiences as a means of facilitating smoother adjustments towards hospice and other care provision. This is important as often many have experienced, loneliness and isolation and may fear 'opening up' to health professions about their thoughts and feelings. Past experience of discrimination from health services may have left individuals quite mistrustful and with limited psychological resources to engage with 'therapeutic' discussions.
8. **Managing the treatment and care experience: the need for helpful, holistic and humanised care**  
Experiences of end of life care varied, depending on the psychological, physical, social and spiritual needs of the person and how those relate to their health condition. It was clear that for many of the participants, stigmatising attitudes still shape the way that many healthcare providers understand and respond to people with substance problems. This is exacerbated

within a fragmented and under resourced health system where the 'snap shot' consultation or hospital encounter are devoid of knowledge about the person's social context. Hospice experiences were positive however, offering a caring environment for individuals to accept their situation and attend to their fundamental care needs. The focus on holistic care within hospices enables each person to be ascribed a 'whole' integrated identity. This does not focus specifically on one stigmatised aspect of their lives, but rather, attends to what can make their life better and more comfortable in the 'here and now.' This also makes individuals less vulnerable to stigmatising attitudes regarding past substance use.

9. For people with substance use problems, receiving an end of life diagnosis may be particularly difficult to cope with because of a range of factors including:
  - Health professionals may not communicate well about their health condition – in part because of their stigmatising attitudes towards substance use but also due to the unpredictable nature of many end of life trajectories for people with substance problems;
  - People with substance problems may struggle to understand the end of life message because: (1) they are anticipating discrimination from the healthcare provider and shutting down emotionally to try to protect themselves from judgemental sources of authority; (2) they may be experiencing memory / cognitive capacity problems; (3) they may have few family / carers around them to help them absorb the information; and (4) they are likely to have presented to healthcare services late, and may Therefore, be very close to death and need to make decisions/plans quite rapidly.
  - Current provision of emotional support may be insufficient for people with problematic substance use, who may be used to being quite secretive over their health and are not used to having to depend upon health practitioners to help them. Indeed, contrary to what health practitioners may expect (about 'demanding / manipulative patients'), they actually often minimise their needs. Thus, there is a need to build trust between PWEs and healthcare professionals to help PWEs overcome feeling marginalised and stigmatised by the health 'system'.
  - This strand of research – into both end of life care **and** substance use treatment care for people with life-shortening conditions – did not uncover much information about end of life care within substance use treatment contexts. This warrants further examination because it suggests that as people with substance problems become increasingly ill, they tend to leave or be discharged from treatment services which are largely unaware of the severity of their health condition(s).
10. Five broad recommendations have been identified for improving the care for people with substance difficulties as they approach the end of their life:
  - i. Understanding identity is important to the provision of effective end of life care. People with substance problems are often reluctant to engage with health and social care services and do not readily identify their substance use as being problematic.
  - ii. Helping people overcome feelings of guilt/self-blame about 'bringing their premature death on themselves' may be especially important if other family or support networks have broken down for them.
  - iii. Considering appropriate health care environments may help to combat loneliness and enhance belonging for people with substance use problems with life-limiting conditions.
  - iv. Adjusting to end of life requires a change in individual focus - from hope (i.e. treatment) to finding refuge and alleviation from loneliness - which can be particularly difficult for people who have substance use problems.
  - v. Finding ways in which people with problematic substance use can feel safe to talk about the dying process and their associated fears must be considered in relation to identity, shame and stigma and self-blame.



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## 1. Introduction

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The programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* (funded by the Big Lottery Fund) has six strands. This report presents findings from Strand 3, which aims to investigate the experiences of people who have or have had alcohol/other drug problems, and who are approaching the end of life. The specific aims for Strand 3 were to:

1. Document how substance use and end of life services have supported people with substance problems and chronic or terminal illness.
2. Report the good practice and challenges that people faced in accessing support services.
3. Provide an opportunity for people reaching the end of their lives to comment on the care and support they received and how that may be improved.

This report has four main sections that cover: background research, methodology, findings, and a discussion/conclusion. The background sets the scene and provides an overview of the existing relevant literature on substance use and end of life care. The methodology section summarises the ethical approval process, recruitment of research participants, data collection and analysis. The findings section presents five main themes: (1) Anticipation of discrimination; (2) Understanding substance use problems within an end of life context; (3) Diagnosis of end of life; (4) Adjusting to end of life, and (5) Treatment and care experiences. These themes are illustrated with verbatim excerpts from the interviews. The discussion section examines the key themes within these findings with reference to potential recommendations for future policy, practice and research.

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## 2. Background

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Problematic substance use and its associations with premature death are significant public health concerns, with alcohol, in particular, being among the top three lifestyle risk factors of death, constituting 10% of the burden of disease and death in the UK (Baker, House of Commons Health Committee, 2017). In 2014, over 11 000 deaths were recorded as related to either alcohol<sup>1</sup> or drug misuse<sup>2</sup> (Office for National Statistics 2016; 2017a). This scale of mortality is not entirely pertinent to work on end of life care as most of the drug-related deaths (in particular) will be sudden deaths and so would not involve end of life care. However, there are also many anticipated deaths among people with substance problems whose life-shortening condition is either not associated with alcohol/other drug or only partially linked – so to that extent the figure of 11 000 deaths is likely to be a substantial under-estimate of the scale of need.

Demographic differences between people who use substances regularly and the rest of the population shed some light on the socio-structural factors influencing substance use. Compared to the general population, frequent drug users are more likely to be male and live in deprived urban areas (Home Office, 2014), with ‘dependent drug users’ most commonly classed as economically inactive (ONS, 2017b). For alcohol, the prevalence of drinking increases with neighbourhood deprivation and is influenced by a population’s ethnic background (being most common among white populations). Levels of alcohol consumption also vary with age and gender: with binge drinking more common among young people, but both frequency and overall quantity of alcohol consumption actually rising with age<sup>3</sup> (PHE, 2016a).

As well as experiencing low socio-economic status, people identified as having substance problems are often stigmatised and marginalised in society (Rance et al., 2017; Room, 2005). The health problems and housing needs that commonly exist alongside substance use problems often compound the negative attitudes and labelling received in relation to substance problems (Room, 2005; Palepu et al., 2013).

In the UK, substance use treatment is delivered by a wide range of statutory, third sector and private providers across community, hospital, inpatient and criminal justice settings - often combining both medical and psychosocial interventions such as: screening and assessment, substitute prescribing, managed dependence withdrawal, rehabilitation, psychological therapies and social support for individuals and families (Department of Health and the Devolved Administrations, 2007). Despite significant reductions in drug use in England (ONS, 2017b), almost 289,000 people were in contact with drug and alcohol services in 2015/16; two thirds of them being male (Public Health England, 2016b). Just over half (52%) were seeking treatment for opiates, with alcohol the second largest treatment

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<sup>1</sup> In 2014, 8,697 alcohol-related deaths were registered in the UK. Alcohol-related deaths include deaths that are registered as being either wholly or partially-attributable to alcohol. The vast majority of these deaths are caused by alcoholic liver disease, fibrosis and cirrhosis of the liver (70-86% depending on whether the death is partially or wholly attributed to alcohol respectively).

<sup>2</sup> Nearly 2,600 drug misuse related deaths were recorded in England and Wales for 2014. ONS data only record acute and directly attributable deaths as drug-related deaths. These are largely deaths through overdose, sepsis or accidents related to drug-taking, and generally would be sudden deaths that could not benefit from end of life care.

<sup>3</sup> Until the age of 75 in men and 65 for women.

need (144,000 individuals). Among the whole treatment population, this alcohol group were older (median age 45 years; 11% being over 60); and just under two thirds of them (59%) sought treatment only for alcohol. The ageing profile of the UK's general population (PHE, 2016c) is mirrored in alcohol and drug treatment populations (Beynon et al., 2010a; Beynon et al 2010b; NHS Digital, 2015; Fuller, 2015). The average age of drug users in treatment has risen to over 40 years old (PHE, 2016b; Home Office, 2014) – partly due to the reduction in younger people using drugs, but also the substantial cohort of heroin users from the 1980s and 1990s surviving into older age.

Palliative care describes the holistic care provided across all stages of a terminal illness (Dixon et al., 2015). Currently the systematic identification of every 'palliative patient' is impossible due to the absence of a standard working definition (Mitchell et al., 2013; Omega, 2010; Shaw et al., 2010; Shipman et al., 2008). In acknowledgement of this, the End of Life Care Strategy (Department of Health, 2008) and the NICE Quality Standard for End of Life Care (NICE, 2011) were both developed to try to improve: (1) recognition of end of life conditions; (2) referrals to end of life care services; and (3) care in the last year of life. These policies also aimed to widen access to end of life care to people with a non-cancer diagnosis and optimise people's choice of where they died. However, people with multiple morbidities and those living in deprived areas are still more likely to die in hospital than at home or in a specialist end of life care service (Higginson et al., 2017). This is probably partly due to people with unstable or less predictable disease progressions having greater likelihood of hospitalisation during an acute episode than people with controllable symptoms who can be managed in the community (Webb et al., 2018). So, whilst the End of Life Care strategy is reducing the number of deaths in hospital, among groups experiencing multi-morbidity or deprivation, the gap in the equality of end of life care is actually widening (Higginson et al., 2017).

## **2.1 Summary: Co-existing problematic substance use and end of life care**

People with both end of life care needs and substance problems are generally not identified by services – either as substance users in end of life care services, or as needing end of life care when accessing substance use services. More significantly: *'an unquantifiable number of people with alcohol/other drug problems may not approach services at all'* (Webb et al., 2018). Current government policy on substance use has adopted a 'recovery' focus (Home Office 2017, Home Office 2012) which is inappropriate for people needing end of life care and fails to address the needs of people who do not access services as currently provided.

Reducing health inequalities is a key objective of the European Policy Framework for health and wellbeing (WHO Europe, 2012), with alcohol-related harm as a key focus (WHO Europe, 2014). Yet within the UK we can identify a clear policy vacuum wherein substance use policy does not account for the needs of people approaching the end of life, and palliative care policy overlooks people with unpredictable life-shortening conditions. This is accompanied by substantial limitations in service provision, not least that the demands of substance use treatment provision may inadvertently exclude people with deteriorating physical health, and palliative care pathways remain heavily focused on cancer care. It is important to remember However, that many people have problems with substances but never engage in treatment. With most academic knowledge generated from the small sub-group of people in treatment, this is likely to skew and perhaps limit our insight.

In summary, despite recognition of the importance of palliative care for an ageing population and government policy seeking to offer high quality palliative care to everyone needing it (Department of Health, 2008), little is known about how to meet the end of life care needs of people with substance use problems. Whilst, the importance of practitioner attitudes in engaging people from a variety of marginalised populations is recognised increasingly as key to effective service delivery (St Mungo's and Marie Curie, 2011; CQC and Faculty for Homeless and Inclusion Health, 2017), the voices of people approaching the end of their life with alcohol/other drug problems remain absent from research and policy (Witham et al., 2018). Our research seeks to instigate development of a knowledge base on how to meet the end of life care needs of people with substance use problems.

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### **3. Methodology**

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As highlighted in the Introduction, this research aimed to document how substance use and end of life services support people with both substance problems and life-shortening conditions in a way that provided an opportunity for them to comment directly on the care and support they received and how that could be improved. As such, we placed great emphasis upon encouraging research participants to ‘tell their story’ in their own words, seeking to keep the interview process as unstructured as possible. This section of the report describes the ethical approval process, interviewee recruitment, the ‘Person-Centred Evolving Method’ approach that we developed for the interview process, data management and our thematic analysis.

#### **3.1 Ethical considerations and approval**

Three main ethical issues were identified. These concerned: (1) individuals who may have felt obligated to hospice or substance use service staff, and so consent to participate in the research without genuinely wanting to; (2) participants’ levels of tiredness, physical discomfort or emotional distress during the interview; and (3) participants feeling upset after the interview because of the topics discussed. In order to ensure that they did not feel obliged to participate in the interview, discussions with both the person referring them to the research team and subsequently with the potential participant themselves, placed great emphasis on the voluntary nature of the interview and the priority given to their wellbeing over the needs of the research project. In order to be responsive to participants’ potential tiredness, physical discomfort or emotional distress during fieldwork, researchers explicitly asked about their ability to continue talking at numerous points throughout the interview, as well as using any visual cues of discomfort to suggest an end to the discussion. Although not actually required during our fieldwork, researchers also put preparations in place for agency staff (referrers) to spend time with any participants post-interview if they were feeling upset due to the topics discussed.

Information sheets, consent forms, semi-structured interview schedules, interviewer lone-working safety procedures and participant distress protocols were all designed for the fieldwork and submitted for ethical approval from Manchester Metropolitan University (which was granted in March 2017).

Throughout the fieldwork period, the research team continuously discussed whether any ethical issues had arisen. Issues identified in this way were also reviewed during our overarching project team meetings to ensure that good practice was followed and that learning from this work was recorded for future use. Informal emotional support was provided between team members as required and regular supervision also provided a potential route for discussing and resolving both ethical issues and the impact of the interviews on the two researchers who conducted the interviews. External counselling provision was also available to the fieldworkers (and indeed, the whole research team), to help manage the potential distress of this work.

It is also important to note the emotional challenges of interviewing people who know that they are at the end of their life. Whilst research protocols were in place to deal with participant distress, they did not cover how to deal with other difficult emotions expressed during the course of interviews, including guilt and regret over substance use and its role in

participants' premature death. Researchers were sometimes left uncertain how best to respond to these disclosures.

### **3.2 Interviewee recruitment**

The process of recruiting and interviewing people at the end of their life was inevitably challenging. Developing good working relationships and maintaining regular contact with our six project partners (three hospices in the Northwest of England, two substance use services in the West Midlands/Northwest of England and a community networking organisation working across Manchester and Warrington). Use of the community networking organisation and community contacts was an intentional recruitment strategy to ensure the research included people not involved with services.

Recruitment was an iterative process using opportunistic sampling (Patton, 1990). Opportunistic (or emergent) sampling describes the process by which researchers make decisions about who to recruit as a research participant during the data collection phase. It often features as part of a wider qualitative research and sampling design, particularly when the work being conducted is exploratory in nature. With little known about end of life care for people with substance difficulties, it was difficult to make firm sampling decisions before the fieldwork got underway. In these circumstances, taking a flexible research design that fostered reflection, encouraged ongoing analysis of the profile of recruited participants, and allowed us to consider making adaptations to the sampling approach, meant that we were able to keep the focus of our enquiry as broad as possible, unconfined by pre-determined selection criteria. As we gained more knowledge of the issues around end of life care for people with substance difficulties, we were able to make more informed sampling decisions that reflected that insight as well as being able to take advantage of opportunities to interview new participants as they unfolded.

People who were known to have both a life shortening condition and a (current or previous) substance use problem were initially approached by a member of staff from the hospice or substance use service they were engaged with, or through an informal contact from a person in a community network. Those showing initial interest in the study were provided with an information sheet and asked to consider whether they would be interested in participating in an interview. If they indicated they were interested, their contact details were passed to a researcher who discussed the research in more detail with them, double-checked that they were happy to proceed, obtained informed consent and made arrangements for the interview.

Although our initial aim was to conduct 20 interviews, given the complexity regarding recruitment in relation to timing, illness and emotional well-being, the completion of 11 in-depth interviews was considered successful with the fieldwork timeframes. Interviews were conducted between April and October 2017 in the Northwest and Midlands of England.

### **3.3 Data collection: conducting sensitive interviews**

Informed by secondary analysis of interviews with relatives bereaved through substance use (Wright et al., 2018) and our reading about deaths of people from substance use (Templeton et al., 2016; Valentine, 2017), a semi-structured interview tool was designed by the strand team and reviewed by another member of the overarching project team who had

conducted interviews with people at end of life for a previous research project. The topic guide covered a range of areas that we wished to explore along with offering participants the freedom to discuss issues relevant to them and highlight things important to them. A copy of the topic guide used for the interviews is appended to this report (Appendix 1), but in brief, the questions related to: (1) experiences of managing health condition(s) and support needs; (2) experiences of support from substance use and/or end of life services; (3) access to support services for people using alcohol/other drugs, and (4) suggestions for improving care and support.

These interviews clearly fall into realm of sensitive interviewing, both intruding into deeply personal experiences and making interviewees vulnerable to emotional turmoil (Drury et al., 2007; Lee and Renzetti, 1990). As such, it was imperative that we worked to a research design that minimised emotional harm for all research participants, and so particular attention was paid to creating a relaxed, comfortable interview experience that was adaptable to each interviewee's preferences. This required a focus on: creating a trusting, empathic space for open discussion; passing as much control as possible over the interview process to the interviewee; and each interviewer staying alert to the impact that the interview was having upon the person being interviewed. We called our approach a 'person-centred evolving method' (PEM) (see figure 1 below).

Central to the 'person-centred evolving method' was our use of informed process consent (Dewing, 2007; Usher and Arthur, 2002) – an ongoing conversation with each interviewee about the aims and design of the interviews and verifying their agreement to participate. Not only was this undertaken at least three times in the run-up to the interview, but it was also touched on again during the interview as particularly sensitive questions were approached. In this way, we were able to remind interviewees that they had a choice to not answer any questions, or even to terminate the interview if they wished. No one took either of these options.

Also inherent to our 'person-centred evolving method' was the focus on building trusting relationships with the hospice and substance use service staff who were gatekeepers to accessing potential interviewees. Not only were they important to the research for granting access, but they also helped us to understand some of the potential vulnerabilities of prospective interviewees and helped us to ensure that interviews took place in pleasant rooms that prioritised interviewee comfort.

Implementation of the interviews themselves followed a complementary approach that prioritised interviewee wellbeing and maximised their control over the research experience. Following the advice of Corbin and Morse (2003), interviewers sought to minimise researcher / participant power differentials - primarily by ensuring that participants had a good understanding of how the interview would proceed and by giving them the authority to change that if they wanted. But another key element to this was through providing a non-judgmental, compassionate space for sharing intimate stories. The research tool had been designed as a semi-structured interview schedule. It framed the interview as an opportunity for participants to reflect and share personal experiences - with explicit permission to express emotions. Interviewers were confident in being able to respond to and 'sit with' distress – in this way sharing acceptance of the potential value of negative emotions. But the team were also clear about the need to avoid colluding in 'narratives of denial' – particularly relevant for interviewees with people with alcohol and other drug problems.

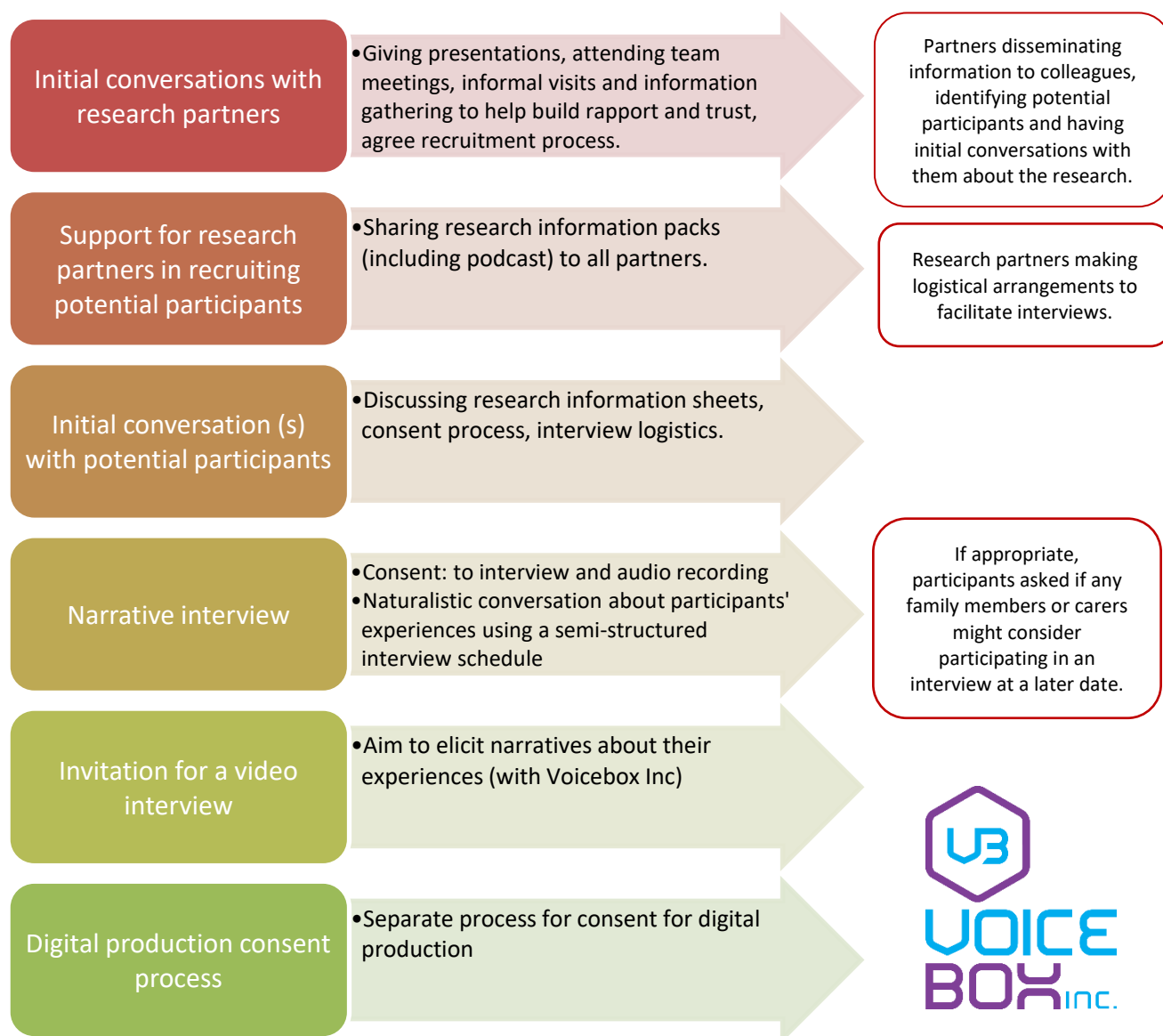


Figure 1: The Person-Centred Evolving Method (PEM) process for our interviews

The flow of the interview also built upon the insight of Corbin and Morse (2003), containing four key phases:

1. Pre-interview phase: Setting the reciprocal research relationship -the extent to which the researcher intends '*being with the participant in the story.*'
2. Tentative phase: Participants adjust storytelling in response to interviewer verbal / nonverbal responses and their own emotions.
3. Immersion phase: Sharing feelings, but researcher maintains empathic distance to be able to provide support.
4. Phase of emergence: Reduced emotional intensity: achieving a level of comfort for both participant and researcher.

Through our team discussions it was agreed by all researchers that given the sensitive nature of the research project, rather than adopt a traditional 'non-intrusive' approach to conducting interviews a more caring and collaborative approach was appropriate. Daley (2012: 33) argues that:



To care for one's participants, and to do as much as possible to enable them to be cared for, is the most ethical response, as it protects and respects the person whose life story has just been shared.

Researchers, therefore, chose to make themselves available to share insights from the research, respond to direct questions and provide information about sources of support that could be tapped into after the interview. The whole ethos behind the interview process was to prioritise interviewee emotional wellbeing over data collection (Daley, 2012; Noddings, 2003).

### **3.4 Data management and analysis**

All social research requires robust management of both interview arrangement information and the data itself, ensuring that data protection measures are adhered to and that participants suffer no adverse consequences from taking part in research. Interviewing on a sensitive topic gives researchers a heightened responsibility for ensuring anonymity and confidentiality for participants (whilst maintaining the boundaries to confidentiality). But it is also incumbent upon researchers to ensure the accurate representation of meaning from the data; and to consider the potential impact of any dissemination and publicity of findings (especially for dissemination over the internet).

Of the 11 interviews completed, ten were conducted face-to-face and one was conducted by telephone. All interviews were audio-recorded and transcribed by an external transcribing agency which had signed a non-disclosure agreement with Manchester Metropolitan University prior to the project starting. Two members of the research team both independently read and coded the whole dataset; comparing and refining their initial codes into a final coding frame that contained all the interview data (see Appendix 2 for merged and agreed final coding frame).

#### **3.4.1 Thematic analysis**

The emphasis of the analysis was towards a 'within case' analysis focusing on individual accounts, rather than a 'cross case' analysis to avoid limiting the findings to mere variables (King and Horrocks, 2010). As suggested by Braun and Clarke (2006) themes from the interviews were identified by adopting an inductive approach to the analysis. Within this approach, themes are generated from the data itself rather than being driven by the researcher's interests or research questions. To this end, 'complete coding' was employed that shifts the focus away from selectively looking for data that the researcher is interested in, to a process where "anything and everything of interest" is coded (Braun and Clarke, 2013: 206).

Data analysis in this way is said to be 'data driven.' However, as Braun and Clarke (2006) point out, researchers can never fully detach themselves from their theoretical and epistemological approaches to their research, thus data can never be analysed in an 'epistemological vacuum' (p. 84). Therefore, it was acknowledged that during the analysis there was a balance to be negotiated between the inductive process and our own research aims and interests. Indeed, as a team, we had begun to develop some ideas from earlier strands of the wider research project (i.e. the rapid evidence assessment and analysis of interviews with family members) and thus cannot not rule out the possibility of these ideas

colouring our analytical approach to the interview data. Nevertheless, during the analysis we had no specific research question in mind and themes were identified through the coding process outlined by Braun and Clarke (2006).

In our searches of the qualitative research literature, it was evident that there were many versions written about how to begin analysing interview data. However, Braun and Clarke (2006) were identified as offering the most comprehensive step-by-step guide to conducting qualitative thematic analysis. Therefore, the analysis presented for this project drew specifically on their approach to qualitative analysis and the resulting six steps of thematic analysis that we took are briefly outlined in table 1 below.

*Table 1: Process of thematic analysis – adapted from Braun and Clarke (2006)*

Phase of analysis	Description of the process
1. Familiarising yourself with the data	Transcribing data, reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire dataset, collecting data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (level 1) and the entire dataset (level 2), generating a thematic map of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back from the analysis to the research question and literature, producing a scholarly report of the analysis.

The *level* of analysis was also considered as outlined by Braun and Clarke (2006). They make the distinction between codes and themes that are identified at a *semantic* or *explicit* level with an analysis that identifies codes and themes on a *latent/interpretative* level. They argue that coding on a semantic level concerns itself with surface meanings of the data without looking beyond what a respondent has said. Conversely, a thematic analysis at the latent level enables the researcher to move beyond surface meanings and begin to explore underlying ideas, assumptions and conceptualisations that theoretically inform the descriptive level of the data. Indeed, Braun and Clarke (2006) identify that this level of data analysis can be located within a constructionist paradigm and as such can provide a useful

foundation for beginning to understand more about how a person can construct their own realities in relation to their end of life/palliative care experiences.

With this agreed approach, the first step of the analysis involved *individual* researchers from within the team reading and re-reading each transcript, making notes in the margins at a descriptive level of the interviewees' responses. These central themes and descriptive codes were collated and developed for each individual transcript and then developed into themes/codes that represented an overarching interpretative theme. These descriptive themes were refined and developed as more transcripts were included and enabled overarching themes to be identified that could then be drawn upon in order to convey a more coherent, focused and representative analysis.

At the end of the *Individual* coding exercise, a second *combined* coding frame was then developed: bringing the first and second researcher's coding frames together. This dual coding approach to the analysis enabled insightful cross-checking of coding strategies and of the interpretation of the data. This was a useful exercise and as is inevitable in qualitative coding, there were differences in the way the data was captured/coded and interpreted. For example out of the 113 descriptive codes generated, approximately 54 codes matched and the remaining 59 were combined codes (highlighted in red in appendix 2). However, as Barbour (2001) points out, the subsequent insights and discussions that occur during the combining of the two coding frames is a valuable stage that helps to refine the final coding frame. Indeed, the research team agreed that the subsequent and lengthy discussing and deliberating of the themes and codes effectively enabled a thorough and detailed account of how the themes were generated.

### **3.5 Strengths and limitations of the research design**

It is important to note that this is a small, geographically limited sample of interviewees. As a result, we are not in a position to claim how the experiences reported here could be generalizable to the wider population of people approaching the end of their life with substance problems. However, the practical challenges of accessing this group of people make these interviews highly valuable. Moreover, the combination of having reached people outside of health services and collected in-depth narrative data (rather than asking them to reply to very structured questions) means that this is ground breaking research despite these limitations.

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## 4. Findings: Sample

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This research successfully recruited 11 people approaching the end of their life who had (current or historical) alcohol/other drug problems. Four people were accessed through community networks, four accessed through a hospice and three through a substance use service. Three other people had consented to participate in an interview, but despite the research team prioritising fieldwork and being able to conduct interviews within a matter of days, the individuals became too ill to participate and/or died beforehand (with one person dying on the actual day set for interview).

We do not know how many potential interviewees were not approached about participating in the research because hospice/substance use service staff judged them to be too ill to be involved. We also gained a detailed case study (see Appendix 3) about another person in the community who was dying from chronic obstructive pulmonary disease (COPD) and could no longer access the substance use service they had been engaging with, with the result that they had been taken off their substitute prescription because they were judged to be not complying with treatment requirements to attend the service and provide urine samples.

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### 4.1 Demographic profile

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The demographic profile of the final interview cohort is summarised in table 2 below. The table reveals that our small group of participants were on average approaching the end of their life 25 years sooner than is expected for the general UK population (which is 79 years for men and 83 for women: Public Health England, 2016c). The group were split almost evenly between people with (current and past) problematic alcohol use and people with (current and past) problematic drug use. Participants were also evenly divided between the three recruitment sources: community network (n=4); hospice (n=4) and substance use service (n=3). Liver failure was the most common life-shortening condition described (n=4), with COPD (n=3) and lung cancer (n=2) being the next most reported health problems. Four of the five people who used drugs had been in contact with treatment services in the past. Three of those four were receiving opiate substitute prescriptions and the other had ceased taking drugs altogether eight years prior to interview. Among those describing problematic alcohol use, five of the six had participated in some form of alcohol treatment over the years, and five of them had not consumed alcohol for at least four months prior to interview.

At the time of interview, six participants were not in touch with substance use services – one of whom had never had any contact with a service. Whilst five of those six were abstinent by that point, for two of them that was largely because their physical ill health prevented them from either accessing or being able to tolerate alcohol/other drugs. Among the five participants who were accessing substance use services, three were receiving a methadone prescription and the two people with alcohol problems were continuing to get support from their local service, despite being abstinent for over a year. This is perhaps a strong indication of the need for ongoing support for this group of people, even after substance use is no longer a feature of their lives.

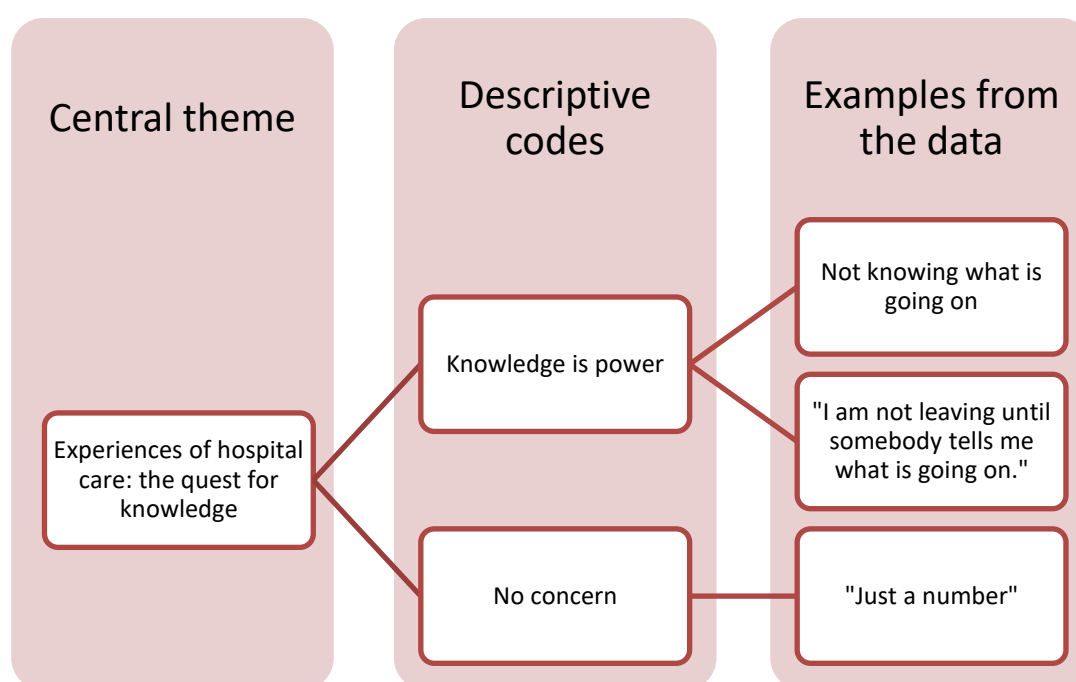
Table 2: Key demographic profile of the participants

Demographic characteristic	Frequency and/or description
Interviewee's gender	<ul style="list-style-type: none"> <li>7 male (64%)</li> <li>4 female (36%)</li> </ul>
Interviewee's age	<ul style="list-style-type: none"> <li>Mean age: 54 years</li> <li>(Range 38 - 71 years)</li> </ul>
Interviewee's alcohol / other drug use	<ul style="list-style-type: none"> <li>5 mainly drug use (3 of them on long-term substitute prescription)</li> <li>4 reported problematic alcohol use 12 months previously (2 of them had stopped 11-12 months prior to interview)</li> <li>2 described historic alcohol problem</li> </ul>
Recruitment source	<ul style="list-style-type: none"> <li>4 via community networking</li> <li>4 via hospice (2 inpatient, 2 day patient)</li> <li>3 via substance use service</li> </ul>
Location of interview	<ul style="list-style-type: none"> <li>5 interviewed at home [1 telephone interview]</li> <li>4 interviewed at the hospice (2 inpatient, 2 day patients)</li> <li>1 interviewed at Substance Use service</li> <li>1 interviewed at nursing home</li> </ul>
Life-shortening condition	<ul style="list-style-type: none"> <li>4 liver failure</li> <li>3 COPD (and other comorbidities)</li> <li>2 lung cancer</li> <li>1 Heart failure</li> <li>1 Multiple sclerosis</li> </ul>
End of life care	<ul style="list-style-type: none"> <li>5 living alone</li> <li>3 living with family ( 1 with partner; 1 with adult child and his partner; 1 with mother who he cares for)</li> <li>2 temporarily hospice inpatients (awaiting move to nursing home)</li> <li>1 residing in nursing home</li> </ul>
Engagement with SU services	<ul style="list-style-type: none"> <li>Four interviewees had been engaged with drug treatment services over many years and received substitute prescriptions. One of them had been abstinent from illegal and prescribed drugs for 8 years.</li> <li>Two interviewees were AA members (one for 30, one for 10 years)</li> <li>One had undergone several (2-3) inpatient detoxes.</li> <li>One had been referred to alcohol service after hospital inpatient stay and had undergone home detox and engaged with the befriending service.</li> <li>One had had brief counselling for alcohol via GP.</li> <li>One had had intermittent engagement with alcohol services, but was currently unable to access services.</li> <li>One interviewee had never had any involvement with substance services.</li> </ul>
Relationship between end of life and alcohol/drug use	<ul style="list-style-type: none"> <li>Ten of the 11 conditions could be linked to substance use (directly or indirectly) if we include use of tobacco.</li> <li>All 4 liver failures were due to alcohol use and the heart failure was due to an infection (presumed to have been caused by injecting). The cases of COPD and lung cancer were probably linked to smoking.</li> </ul>

## 4.2 The application of thematic analysis

This section describes the process through which we undertook thematic analysis with our transcribed interviews.

Once familiarised with the transcripts on a descriptive level, the next step was to develop codes from our descriptive notes. As an example, we present the early stage of coding for one of our research participants – Barbara. This reveals how excerpts from the transcript are used to form: (1) descriptive codes, and (2) an overarching ‘central’ theme. In Barbara’s account for example, there were themes that related to experiences of hospital care. Excerpts from a section of her interview are presented in figure 2 below to demonstrate the building of the coding frame:



*Figure 2: Initial codes developed in the example of Barbara’s interview transcript*

Starting with 108 initial descriptive (‘child’) codes that had been iteratively identified from all of the transcripts, these codes were collated into 17 interpretative (‘parent’) codes which were then clustered into five central themes (‘grandparent’ codes). These central themes comprised the totality of the interview data and specifically addressed the aims of our work, in terms of understanding how people with alcohol/drug problems (past or present), experience end of life care or substance use treatment. This coding work is presented in appendix 2. All of the codes within the coding tree were then reviewed to check that at each level they were: (1) clearly described with a shared understanding of the inclusion/exclusion criteria in order to ensure that the content was consistent; (2) not missing data that could justifiably be included; and (3) sufficiently distinguishable from other themes (whilst allowing for a necessary level of overlap).

This initial analysis allowed us to explore different potential orderings for ‘telling the data story’ and the final analysis of coded material included the selection of verbatim excerpts from the transcripts to demonstrate key findings in relation to the aims of the research.

We now turn to consider our findings from the interviews. After briefing summarising key information about the individual research participants, we present our findings in relation to the content of the interviews themselves.

## 5. Findings: Key themes

This section presents the findings for this research. This commences by introducing the research participants to briefly summarise their substance use and treatment history, as well as their health status and end of life situation at the time of interview. Then we present our findings using the five central themes of: Anticipation of discrimination; Understanding substance use and end of life care nexus; End of life communication; Adjusting to end of life and end of life care needs; and Managing the treatment and care experience: the need for helpful, holistic and humanised care.

Throughout the next sections of the report, all quotes have been anonymised and pseudonyms are used that bear no relation to the participants' actual names.

### 5.1 Introducing the Participants

Before considering the thematic findings of our research, Table 3 presents a brief summary for each individual research participant.

*Table 3: Summary of participants' substance use history and health condition at time of interview*

Pseudonym	Precis of substance use and treatment	Precis of health condition and end of life situation
Steven, 38	Steven has been using alcohol heavily for many years although he has stopped drinking in recent months due to his severe ill health. He had undergone residential detox a few times over the years, but never had funding for longer-term rehabilitation. He has not sought treatment for his alcohol use recently.	About 12 months ago, having seen his GP because of severe pain, Steven was sent to the hospital where he was told that he had liver failure and had about six months to live. He spent eight weeks as a temporary inpatient in his local hospice to give his Mum some respite, then moved to a nursing home, but planned to return to the hospice for his end of life care.
Gill, 57	Gill has drunk several cans of lager daily throughout her working life. In the past she had seen an alcohol counsellor for six weeks at her GP's practice. Whilst able to reduce her consumption, Gill did not want to stop drinking. She has had no alcohol treatment since then and drinks daily. Gill was very open about her psychological dependence on alcohol.	Despite coughing up blood, Gill did not go to her GP until she also had a shoulder pain. She was diagnosed with lung cancer that had spread to her lymph nodes. Gill didn't tell her family about her diagnosis for a month. She has been treated by two hospitals and was receiving pain management through her local hospice.



Pseudonym	Precis of substance use and treatment	Precis of health condition and end of life situation
<b>Rob, 42</b>	Rob had been an injecting drug user since the age of 20. He had had periods of a few years of abstinence, but never felt able to 'fully' give it up. Rob accessed substance use treatment after being hospitalised and is now receiving a methadone prescription.	Eight months prior to interview, Rob woke up in hospital to find he'd had open heart surgery due to endocarditis. Six months into his outpatient care, a nurse asked if he wanted to attend a hospice, assuming that he knew he only had 1-3 years left to live. Rob subsequently began participating in the hospice's 16 week day programme.
<b>Nicola, 57</b>	Nicola was a frequent recreational drug user and daily cannabis smoker from being a young woman. She has never sought treatment for her drug use.	About five years ago Nicola was diagnosed with Multiple Sclerosis (MS). Cannabis helped her manage her MS symptoms and acted as an anti-depressant. But as her functioning reduced, she could no longer access it. For the last three years she has had very limited function from her neck down and currently lives in a nursing home.
<b>Nigel, 55</b>	Nigel has been a heroin user for many years. He lives with his elderly mother and is her principle carer, a responsibility that acts to keep his drug use controlled. Nigel is prescribed an opioid substitute through his substance use service, but feels that other than checking he gives clean urine samples, his key worker never asks him about his physical health.	Nigel has several chronic physical health conditions including diabetes, COPD, cardiovascular disease and circulatory problems associated with his diabetes. He does not particularly pay attention to his own healthcare needs as he feels his main focus should be on caring for his ailing mother. His GP and diabetes nurse do not ask him about his drug use.
<b>Barry, 71,</b>	Barry was an exceptionally heavy drinker from his teens until the late 1980s, with several periods in hospital alcohol treatment units, ultimately being sectioned in a psychiatric unit. After collapsing following another binge drinking episode (where he thought that he was dying), he joined Alcoholics Anonymous (AA) and has not drunk since (30 years).	Barry has COPD and an unstable (and un-operable) aneurysm in his main artery. The community respiratory team visit him at home, and Barry phones them when he needs a visit. Whilst currently under the care of his local hospital, the complexity of his health situation has resulted in a fragmented experience of treatment.
<b>Susan, 57,</b>	Susan began drinking in her late 30s as her marriage became problematic. For a couple of years she drank heavily, trying to hide it from her family and her abusive husband. Eventually her adult daughter from a previous relationship got her a place in residential detox unit and she completed several months in rehabilitation as well. She then lived with her daughter (and her young family) for a while before getting her own place. She has not drunk alcohol in 10 years.	Over the past few years, Susan has been diagnosed with rheumatoid arthritis, osteoporosis and fibromyalgia. After nine pneumonia-related hospital admittances in eight months, Susan caught sight of her lung x-ray and asked the consultant whether she needed to tell her family how serious her health condition was. He said 'Yes.' Susan started receiving oxygen therapy at home and attending the hospice day programme. Her adult daughter provides care for her.
<b>Peter, late 50s</b>	Peter has been a heavy alcohol drinker throughout his adult life. He had periodically engaged with the local substance use service,	Peter has had recurrent hospitalisations after being injured from falls due to peripheral neuropathy (damage to peripheral nerves causing

Pseudonym	Precis of substance use and treatment	Precis of health condition and end of life situation
	and ceased drinking between 2011 and 2016. A year ago he left his partner and after a brief relapse, stopped drinking and started attending the substance use service again.	weakness and pain in hands and feet) in his feet. He has recently been told that his liver is irreparably damaged, and has a second gastroenterology appointment soon. His alcohol worker thinks Peter may either have had a stroke or be suffering from alcohol-related brain damage (possibly Wernicke's encephalopathy <sup>4</sup> ). His worker thinks Peter should be in a care home as his current care package is fragmented.
<b>Richard, 67</b>	Richard has a long history of heroin and other drug use, but has not used any drugs for eight years. He and his wife had used drugs together and had both been engaged with treatment services for many years. As they stopped using, they started volunteering for local drug services and have continued to have some informal links since then.	Three years ago Richard was diagnosed with lung cancer. After having chemotherapy and participating in a new treatment trial, Richard was recently told that there was nothing more that could be done to actively treat him. He and his wife are being supported by hospital cancer nurses and the hospice community team. Richard wants to die at home.
<b>Barbara, 55</b>	Having been a social drinker, Barbara developed an alcohol problem as her marriage began to break down in 2004. With the help of the alcohol service, Barbara stopped drinking in 2008 but relapsed in 2012, which resulted in her being hospitalised again. Following a home detox, she relapsed after a stressful event in 2015 and has been receiving support from the alcohol service since then. She has now stopped drinking.	Barbara was diagnosed with liver cirrhosis in 2008. It was only on her second hospital admittance, when she refused to leave until someone explained what was happening to her body, that the hospital brought in the local alcohol support service. Following recent internet research on the British Liver Trust website, Barbara asked her GP for a liver function test and referral to specialist liver unit. She now has a diagnosis of end stage liver disease and hepatic encephalopathy. She also has peripheral neuropathy, sleeping difficulties and osteopenia <sup>5</sup> .
<b>Daniel, 41,</b>	Daniel has been a heroin user since he was 15. He has been in drug treatment several times, but never managed to abstain from	Daniel found out that he had hepatitis B and C almost a decade ago and is under the care of his local hospital's liver unit. At home he is

<sup>4</sup> Wernicke's encephalopathy (WE) is the presence of initially reversible neurological symptoms caused by biochemical lesions of the central nervous system. These arise due to the exhaustion of B-vitamin reserves, in particular thiamine (vitamin B1), which are often the result of problematic alcohol use (particularly where diet is poor). Neurocognitive symptoms typically include mental status changes (which may include delirium), poor physical coordination and unsteadiness (arising from the brain's failure to regulate the body's posture and regulate the strength and direction of limb movements), and uncontrolled eye movements. If untreated, Wernicke's encephalopathy can develop into the much more serious and irreversible Korsakoff's psychosis. As such, Wernicke's encephalopathy is considered to be the first of two separate parts of a spectrum of disease, referred to as Wernicke-Korsakoff syndrome (WKS).

<sup>5</sup> Osteopenia refers to decreased bone density but not to the extent of osteoporosis. This decreased bone density leads to bone fragility and an increased chance of breaking a bone (fracture).

Pseudonym	Precis of substance use and treatment	Precis of health condition and end of life situation
	drugs. Over the past ten years he started drinking alcohol as well, but his mother's terminal illness has motivated him to become abstinent before she dies. Daniel has now been engaged with the substance use service for two years: receiving methadone treatment, key worker support and attending an art group. He has stopped drinking.	assisted by a carer for 10 hours a week who makes sure he attends all his appointments and supports him with some social activities. Daniel understands that he is not going to recover and fortunately his carer has had end of life training and so they have both recently attended a Death Café (where people can gather to drink tea, eat cake and talk about death) as a first step in beginning to plan for a good death.

In summary, table 3 reveals the profile of a diverse group of people, some of whom had successfully abstained from substance use years prior to interview, others who had not. Many of them were reluctant to seek medical assistance, turning to friends and family for informal care, rather than approaching GPs or hospitals. Whilst some of them described family breakdown, for the women in particular this seemed to cause (or exacerbate) substance use, rather than result from it. Other participants described some very strong, positive relationships, albeit sometimes with close friends rather than relatives. All of the people we interviewed had complex health and social care needs – many of which had existed for many years prior to them approaching the end of their life. Where participants had been involved with health services about their deteriorating health, there were clear examples of poor communication, minimal and fragmented care and a failure to refer on to substance use services. But there are also some examples of excellent care, such as Daniel's carer who helped him not only to remember and attend medical and substance treatment appointments, but also to participate in social activities that enriched his life and to face up to and plan for the end of his life.

## 5.2 Presenting the Themes

In this section, we present the overarching, final thematic diagram of the analysis before moving onto the analysis of individual themes. There were recurring themes evident across the 11 interviews that specifically provided insight into participant's experiences of end of life care. In total five key themes were identified:

1. Anticipation of discrimination
2. Understanding substance use and end of life care nexus
3. End of life communication
4. Adjusting to end of life and end of life care needs
5. Managing the treatment and care experience: the need for helpful, holistic and humanised care

**Carrying a  
substance  
use identity**

After joint discussions with the research team, it was evident however, that as the analysis developed across the 11 interviews, data relating to *problematic substance use and identity* featured predominantly across all themes whichever way we organised the data. Thus, a central integrative theme (King and Horrocks 2010) of '*carrying a substance use identity*' was added to the final thematic diagram (figure 3 below). This is something that Braun and Clarke (2013: 224) would define as a '*feature*' of the data rather than a theme, as it captured a finding that recurred throughout the majority of the interview data.

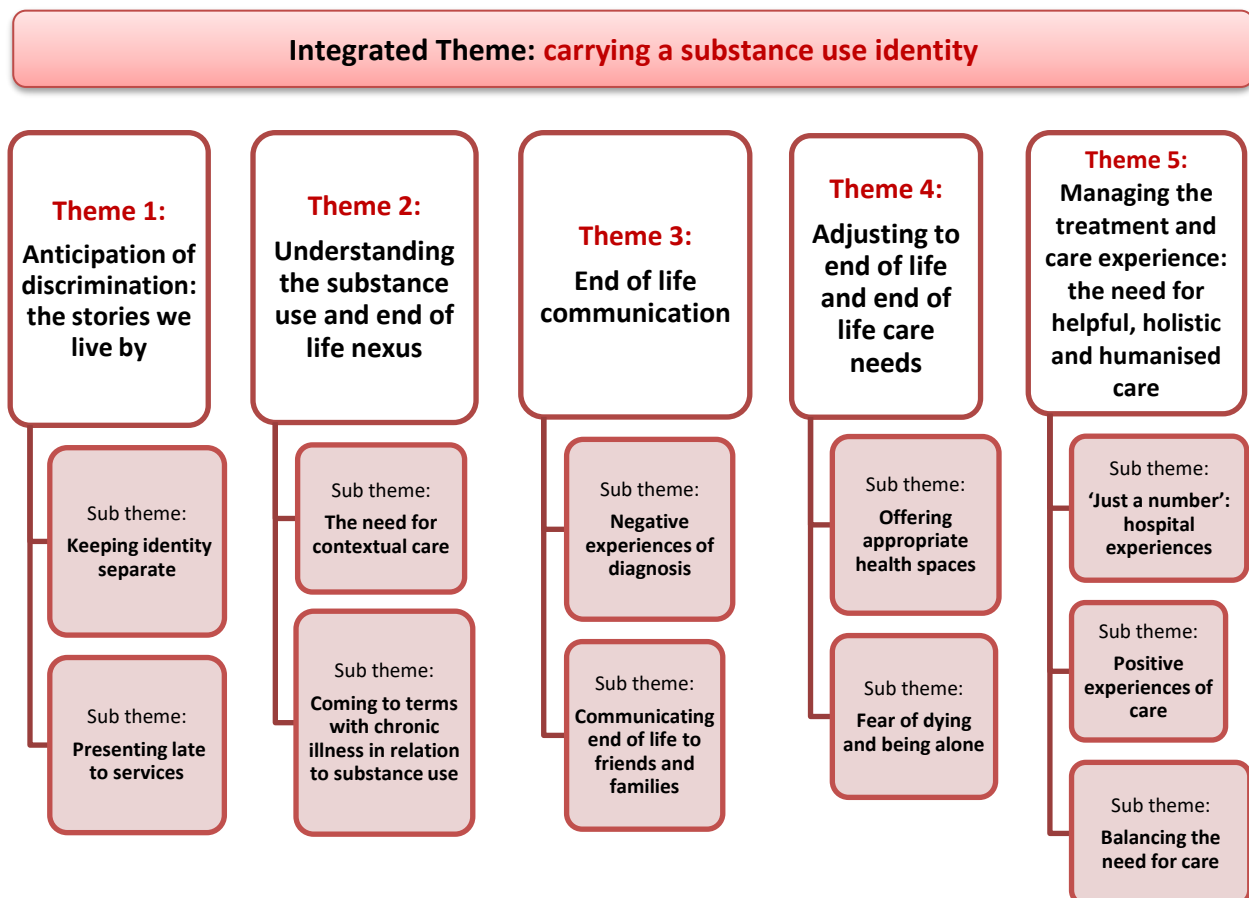


Figure 3: Main analytical themes sub-themes and integrated theme

## Theme 1: Anticipation of discrimination: the stories we live by

Although 'carrying a substance user identity' was a feature of the data that cut across all themes, '*anticipation of discrimination*' was considered a theme as it reflected something more meaningful in relation to how the people we interviewed experienced end of life care and the services they came into contact with, or Indeed, did not.

Richard was diagnosed with cancer two years prior to the interview, and he had recently been told that there was nothing more that could be done in terms of active treatment. Both Richard and his wife talked about having been treated '*pretty badly*' through discrimination when picking up methadone prescriptions from pharmacies in the past and how their substance use identity still follows them:

PWE:   Wherever I go, whatever stuff I do and I suppose that's it, just a bottom line, there's an element of guilt or something there, just constantly or you know... and it's a fact thing, you know what I mean, it's like where I've been, what I've done, so and so forth you know and that's it.

Wife:   It takes a long time doesn't it, to get past what you've experienced before, for over many years of being involved with professionals who, a few years ago would treat you like pretty badly wouldn't they?

PWE:   ... And, wouldn't take you seriously and they wouldn't, you were never believed and you were always made to feel like rubbish and it takes a lot to get past that and then start maybe putting a bit more trust in these people again, if you ever do.

(Richard and wife)

Although their experience of discrimination was an historical account set in the context of drug treatment not end of life care, their account demonstrates the *anticipation* of discrimination and how that can affect current relationships with 'professionals'. Richard in the above quote used the word '*fact*' to express the perceived normality of expected discrimination as '*just a bottom line*' and consequentially, how difficult it can be to build trust with professionals involved in his current health care. Indeed, because of the culturally endorsed stereotypes that surround problematic substance use - often treated as a moral and criminal issue rather than a health concern - a concerted effort to resist taking up such identities that may result in poorer health care was described:

No I mean, the drug thing we both used together, we had a period of a good few years didn't we, of using, and whatever, that brought us to on these ... and we came out of that, we managed to get clean and end up here and stuff, and whatever, so we've been through that journey and we've been many other things in our lives ... we refuse to be labelled as a drug user or ex-drug users, no, I'm an ex-many things.

(Richard)

In the transcript excerpt above, Richard points out that he and his wife have '*been many other things in our lives*.' Thus, there was a quest for others to acknowledge personal context in order to avoid falling into essentialist notions of people with substance use problems as somewhat fixed and one-dimensional in character. In this current project, experiencing stigma or Indeed, *anticipating* stigma and discrimination was evident in the

majority of our interviews, particularly in relation to acute and outpatient hospital care. Rob for example, talked about his experience in hospital and the care he received:

I've been in hospital a few times on and off over the years for all kinds of different things but as I say, I've never been a problem patient ... [it's] on record, on my files [that I'm] an IV [injecting] user and yet they were giving me morphine ... but the fact that I wasn't abusing it, I wasn't asking for it every two minutes ... These look at me just like the next man ... maybe the majority of them have no reason to have access to my file.

(Rob)

As the above quote highlights, it was clear that Rob was keen to position himself as a good patient – similar to Richard earlier. There appeared to be a concerted effort to ensure that staff at the hospital did not see him as a 'problem patient'. However, what was interesting to note in Rob's account, was that he was able to take up the position of 'good patient' more readily because he suspected that the hospital staff had not read his records and consequently could 'look at me just like the next man'. Thus, there was with Rob, as with others we interviewed, a tendency towards regulating and managing the anticipation of discrimination, as Rob implied that if staff had read his files, he may have been treated differently. Richard's wife later on in their conversation highlighted similar concerns and talked about the efforts they made to ensure that they were not 'scaring' people off with their 'junkie' identity – a term often associated with drug use and crime (Radcliffe and Stevens, 2008):

You make that effort to give a good, what's the word I'm looking for? Like a good perception of yourself, like to, so you're not scaring them off, because a lot of people or doctors, people in those positions look at you and think, "Oh junkie. Right."

(Richard's wife)

Social identity theory within substance use literature has been talked about and considered for many years, dating back to the mid-1980s. McIntosh and McKeganey (2001), drawing on Goffman's (1963) work maintained that people with substance use problems have a 'spoiled identity' and that any such recovery from substance misuse would need to involve a restoration of such an identity. However, the effect and impact of such viewpoints can lead to an absence of acknowledgement of other positive identities such as 'mother', 'father', grandparent', 'wife', 'husband' and so on.

There has been a later shift in acknowledging social context and recognising that identities can be more fluid and interchangeable (Burr, 2003), yet such consideration can be 'lost' when people with substance use problems have 'surfaced waves of public concern' from disease states to criminality (Changing Minds Campaign, 2003) that sustains such a spoiled identity (Radcliffe and Stevens, 2008). When problematic substance use is connected in such ways, it is argued that there becomes less hope for de-stigmatisation. Indeed, research evidence highlights that problematic substance use is more likely to be stigmatised than other health conditions (Livingstone, Milne, Fang and Amari, 2012) and as such, the potential to build positive relationships with, for example, health professionals, can be difficult.

### **T1.1 Keeping identities separate – passing as ‘normal’**

In some circumstances, the people we interviewed were engaged with multiple services such as substance misuse services, hospices and hospitals that were separate in terms of their particular health care focus. During these varied encounters it was evident that managing separate identities was another way of managing the anticipation of discrimination. For example Rob talked about being more comfortable when he managed to keep his ‘identities’ separated; in this way, at the hospice he was simply Rob:

‘I’ve got a knackered heart not ‘Hi I’m [Rob] I’ve got a knackered heart and I’m a recovering heroin addict.’ It’s not a title that needs to be thrown onto the end of my heart thing. My heart thing is why I am here, I’m not here for my substance abuse, I go somewhere else and I get treatment for that.’  
(Rob)

In the hospice Rob was very clear that he was there because he had undergone heart surgery and that in the hospice Rob the ‘*addict*’ was an identity that:

Doesn’t rear its ugly head here, it has no need to rear its ugly head and it’s getting its ugliness dealt with elsewhere. It could only be detrimental for me to bring it up or make other people aware of it, especially other patients, it could only be detrimental in my opinion because everybody isn’t all: “Good on you, you’re a recovering addict, stay strong.” You’re going to get people who are going to [say] “Smack-heads, where’s my phone, the smack-head’s took it.”  
(Rob)

For Rob, the ‘spoiled identity’ and ‘ugliness’ of a recovering heroin addict had no place in the hospice. Indeed, revealing past drug use was described as ‘detrimental’ for Rob in a space where he was receiving help for his heart condition. In this way, Rob was perhaps able to pass as ‘normal’, as having heart failure was more appropriate for the setting, and thus there would be fewer opportunities to be positioned as a failure, a ‘smack-head’ or a thief, more stereotypically associated with people who misuse heroin. Therefore, the anticipation of discrimination was consciously managed and for Rob, his substance using identity was appropriately minimised.

### **T1.2 Presenting late to services**

One of the main detrimental effects of stigma on people with substance misuse problems is the perceived or experienced barrier to accessing treatment from health care providers. Both Richard and his wife described having to fight for change in relation to tackling stigma within the healthcare systems to try to reduce barriers of engagement:

We’ve always felt that’s part of our duty ... to make way and change that thing with pharmacists and things isn’t it? It’s like voluntary work we did and the organisations, it was about changing the attitude of pharmacists, when you, people, clients going in, in the morning and getting their methadone. We’ve been treated so badly in the past, but we fought hard

to get that changed ... an organisation we were with, just being told to wait outside in the rain, so they dealt with a normal person ... then get called in ... someone else might come in, you're told to wait. From that to now where you go in and you have a room and it's private rather than, so it's taken a number of years for some of those things to change.

(Richard)

Livingstone et al. (2012) noted that research has revealed that health care providers may hold negative views about people with substance misuse problems, including that they over-use resources; are not committed to improving their own health; use the health system divisively to access drugs and do not take on health advice. Above, Richard described how the treatment process of methadone replacement prescription can itself be stigmatising having experienced segregation in the pharmacy, separating him from the 'normal person'. The constant shifting, balancing and negotiating of identity seemed to reflect a broader sense of illegitimacy for many of the people we interviewed in terms of accessing or deserving care. Having experienced this kind of stigma, it can understandably lead individuals to conceal their actual substance misusing behaviour and to present to health care services much later, and potentially at a more acute stage than non-substance using people. Indeed, some of the people we interviewed were clearly unwell by the time they had begun to access services in relation to their chronic illness. Steven, for example, was in a hospice at the time of his interview, yet it was not until he had 'gone bright yellow' and was in severe pain that he went into hospital:

It were just before Christmas, I got took into hospital, I'd gone bright yellow, I'd been drinking, I was in that much pain, I didn't know it was actually coming from my liver and I was taking a load of morphine and stuff for the pain, I sort of OD'd [overdosed] myself a bit on all the painkillers, not realising what I was doing because I was drinking as well.

(Steven, TR01)

Further on in his interview Steven described being ill for a long time prior to his admission to the hospice:

STEVEN: I felt really ill, so they brought me in here [hospice] and I was very ill at the time and I'm not ready to get myself ticking over again, it took a while though, I'm fighting it a little bit but it won't ... but I've held it for so long, very long ....that was the last time that I drank then, I just stopped drinking then, I come out of there at the start of the new year, I got home for about a week and then I come in here but I didn't even touch a drink for a week, when I were at home ...

MOTHER: You were quite ill weren't you?

STEVEN: I was so ill.

Similar to Steven, Gill did not seek out health advice about her shoulder pain even when she started coughing up blood. It was only when the blood had started getting darker that she went to see her GP:



INT: You mentioned about 18 months ago you got diagnosed?

GILL: Yes with cancer, yes

INT: What happened, what was the kind of run up to finding out about that?

GILL: I worked on the market ... I thought I'd pulled me shoulder, like something in me back there, it was bloody killing me for ages. I kept saying I'll wait until the season finishes, this was about a month before, so I put up with it. But before that I started coughing up blood. I thought "this is not normal". Anyway at first it was just red blood and then it started getting darker and darker.

(Gill)

Rob initially thought he had flu but when his health began to decline further, Rob did not consult a doctor. His excerpt below suggests that he was clearly worried about what was happening and did not want to be on his own, yet he took himself to a friend's house so that they could 'keep an eye on me' rather than going to a GP or hospital:

It pretty much all started about May this year, I was ill for about ten days with flu-like symptoms but I'm not a man-flu type person and this was quite severe. What had struck me down, there was other things like vomiting that made me think it wasn't just flu. Just over a week and I went to a friend's and said "do you mind if I stay for a few days? I'm really not feeling good", I live on my own and I should put that in. I said "I'd just feel a bit better if there was somebody to keep an eye on me" and he said "yes", obviously "stay as long as you like."

(Rob)

Rob was very ill and ended up having to be rushed to hospital where he underwent open-heart surgery and did not wake up until eight days after the surgery.

Several participants described trying to continue caring for themselves at home with little or no formal support, only accessing emergency health services when an acute health crisis made that necessary. For example, participants such as Barbara attended hospital due to ascites; Nicola was taken to hospital with blood loss; and Susan was hospitalised with COPD. Several participants were also very conscious of the impact of their health upon family members; either the growing strain upon others in terms of having to look after their (participants') failing health or their own need to be fit enough to care for family members. For example, Steven, began to recognise the strain that caring for him was placing upon his mother that led him to go into the hospice, and for both Daniel and Nigel, it was their mothers' deteriorating health that drove them to take care of themselves

### **T1.3 Summary: Implications of a 'spoiled identity' for people with substance use problems at the end of life**

It was clear from the interviews that for many people there was a sense of having to manage the anticipation of discrimination at a time in their lives when a secure and comforting base is needed. Goffman's (1963) concept of the spoiled identity considers the discredited person whereby the source of shame is actively concealed or hidden in order to maintain 'passing as normal'. Thus, any information regarding the source of shame must be managed and negotiated as exemplified in Richard and Rob's accounts above. This can

create problems for people with substance use problems who may avoid early conversations around their health conditions and particularly for those who are having to come to terms with an end of life diagnosis. Anticipation of discrimination brings with it a sense of mistrust and misunderstanding that can have consequences for early or timely engagement with health services and other support services. Understanding identity within this theme is important if contextual and holistic care is the goal of health care services. This will be explored further in subsequent themes.

## **Theme 2: Understanding the substance use and end of life care nexus**

Participant's problematic substance use included single use, or a combination, of: alcohol, heroin, methadone and cannabis. The majority of the participants had long histories of problematic use and talked about how dependency had developed over the years. The interviews enabled us to understand more about the participants' social context, a perspective that participants were keen for us to know and understand, resulting in the majority of our interviews beginning with, or including, a 'back story' of their lives. The integrated theme 'carrying a substance use identity' was evident within this theme of beginning to understand some of the implications of substance use problems for people who are chronically ill or at end of life.

### **T2.1 The need for contextual care**

Barbara's drinking became problematic as a result of suffering from domestic abuse from her previous marriage over 10 years ago. The conversation during the interview with Barbara included her reflections on how her alcohol dependency had developed:

This is where the drink kicked in, to cope with it because I could not cope, I didn't know what to do ... my only way of dealing with it was drink, drink, drink, drink, but I became dependent, but at that particular time, I didn't know what alcohol dependency was, I was like yes, I knew I'd got a drink problem but I wasn't..., I wasn't ... I didn't go to the doctors because I didn't think a doctor was needed, I just had this dependency on alcohol because every time I stopped drinking, every time I got up in the morning, I'd start to shake, "what the hell's this" "what's this?", and I'd have panic attacks and I'm thinking "what's this" I didn't know what a panic was and so my coping mechanism was "Ooh if I have a drink, the panic attack goes away" and that was how it started.

(Barbara)

Because of my marriage, drink was my only way that I thought I could cope with the problems that I was going through, which led me to become a full blown alcoholic.

(Barbara)

Barbara's account is interesting as she talks about not knowing what was happening at the time and did not 'know what alcohol dependency was'. This can often be the case with people who are using alcohol as a way of coping with social problems, that the initial dependency is not noticed until serious health problems occur. Similarly, Susan's telling of her 'back story' began when she was in an orphanage as a child, she had suffered from Tuberculosis and her father was imprisoned for sexually abusing her sister. Susan later

suffered from an abusive relationship and talked about how her drinking developed over the years as a 'comforter' whilst having to care for her disabled son:

You just do take to it, as a comforter or to mask things, not to feel anything that you're feeling.

After we'd been together a few years he started being really ... sort of domineering, you know, making me feel like I had to do things to please him again because if I didn't, he'd make my life hell and even my sons are wary of him still because they still live there.  
(Susan)

Gill further on in her interview talked about how her carer for her disabled son resigned because she could not bear to witness the husband's bullying:

She said to me, "I'm going to have to finish." I said "You're not, no, please." She said "I've got to because he's a bully, that's what he is." And she sat down and she said, "It's no wonder the way you are, it really isn't." And I said "But it's him that's doing it." She said "He's a bully, I cannot work here and watch the way that he treats you anymore." And she finished because she was getting depressed, seeing it all.  
(Susan)

Moreover, Peter and Barry's accounts echoed intergenerational substance misuse problems where families can be seen as risk factors that heavily influence vulnerability to problematic substance use:

I've been a drinker all my life, my father died of cirrhosis of the liver. But I were brought up with drink. And I've got two sisters, they're alcoholics, my brother, he's an alcoholic.  
(Peter)

Barry talked about his father's alcohol use and how it runs through the family, he was also concerned that his daughter had an alcohol problem, in the excerpt below, Barry is trying to comfort his daughter who had recently overdosed,

I said "Come on" she kept saying "I'm sorry Dad, I'm sorry Dad", So I tried to explain to her, I said "I'm the youngest of 10 the other nine doesn't drink and I finished up like my Dad" ... I said to her "You've got my genes, you don't have to apologise".  
(Barry)

Within a traditional framework of problematic drug use, Barbara, Gill, Barry and Peter would be considered to be people who have made poor choices and allowed themselves to drift into alcohol addiction. However, it is clear to see from the above excerpts of their 'back stories' that for Barbara and Gill, consuming alcohol was a choice pattern that appeared appropriate at that particular time in their lives. Similarly Barry and Peter who were 'brought up with drink' would have had limited opportunities to exercise choices not to drink in a household of 'alcoholics'.

Thus, rather than framing substance use dependency as a 'choice' and a self-inflicted behaviour that warrants little sympathy, through such contextual information, a different insight is offered. Such insights – or re-framings – can be important for health care providers as they enable better relationships to form around trust, care and compassion. Indeed, Buchanan (2004:1) succinctly argues that there is a need to move away from individualised approaches that: 'may inadvertently pathologise problem drug use by narrowing the focus and attention towards the individual, their choices and their motivation to change'. Therefore, when considering treatment and care for chronic illness: 'it must be recognised that many problem drug users have had such limited options in life that they lack personal resources (confidence, social skills and life skills) and have limited positive life experiences to lean upon or return to.' (Buchanan, 2004: 4).

## **T2.2 Coming to terms with chronic illness in relation to substance misuse**

Out of the 11 people we interviewed seven participants had ceased their substance use prior to their diagnosis/health condition yet this was largely due to increasing ill health at which point many of them had become too ill to access treatment services. Understandably, thinking about making positive changes in relation to substance misuse problems at a chronically ill point in a person's life presents a multitude of challenges. The late presentation of chronic illness combined with a long history of relief drinking/drug taking was difficult for some people to come to terms with at this particular time in their lives:

STEVEN: I've been trying to come off the drink and then in my head, I was in that much pain I thought "Let's have a drink." So I could calm my nerves down and calm my pain down as well, it was a mixture of both of them because I was just ... everything up. If I'd have just left the drink now, I should have been have been okay when I found out last year.

INT: Was that the first time that anyone had said to you about alcohol causing your liver problems?

STEVEN: No, no. I've been to rehab a few times, ... I've been there. I got told and told and told but you think "I'll be okay, I'll be okay." But you won't be.

Steven above was being cared for in a hospice at the time of his interview and although he was struggling to come to terms with his illness in relation to his drinking, he was accepting that he was 'very ill' and retrospectively wishing that things were different:

I got told and told and told but never listened, so it just got worse and worse and worse and now, I wish I would have listened. I wish now I had time enough to help someone else through it ... But I just wish, I wasn't like this, I'm only 38.  
(Steven)

Clearly Steven was reflecting on previous opportunities to try and change his drinking behaviour, but with a long history of misusing alcohol combined with his current health problems, Steven found this difficult, particularly coupled with managing the pain he was in:

Very hard, it's up and down but pain wise it's been horrific.  
(Steven)

In contrast to Steven, Gill's account was much more optimistic. Gill was very open and honest about her drinking behaviour at that time in her life:

Like I drink alcohol all day, I'd say about four cans during the day, which I can have, but it never feels like I've had a drink. But that is me, that's my life and everything, so I'm doing very, very well at the moment. The doctor says to me, "Don't give up drinking, don't give up smoking because it will upset me system, and you're too far gone now, so you might as well enjoy what you enjoy and you like it." So, I'm doing that, I had no intentions of giving up anyway. But that is my life, alcohol and me fag. That's me first two things in life.

They've asked me would I like to stop and I just say: "No I don't." "But what if it kills you?" I say "Well if it kills me, I don't want to stop."  
(Gill)

Gill clearly had no intentions of 'giving up', and her oncology consultant appeared to support this. For Gill, it is understandable that any attempts to change her behaviour regarding alcohol would perhaps be futile as she was '*too far gone now*', and Gill was clearly happy to continue with her 'alcohol and me fag' as the two priorities in her life. Thus, for Gill, her end of life experience was about enabling her to enjoy the time of life she had left with the support of her consultant. Indeed, being able to have such frank discussions and personal support for her choices seemed to enable a better relationship with her consultant and perhaps more frank and open discussions about her care that resulted in her 'doing very well'. Rob on the other hand who had damage to his heart from infection following injecting drugs appeared much more motivated to improve his health and was able to discuss support whilst in hospital:

I've been an on/off recovering addict since 18, 20, I've had periods of sobriety for a couple of years, two or three years here, a year there on and off but it's just been a crutch that I've not fully been able to kick until this has happened and it's, I suppose it does take something drastic before you really do wake up and smell the coffee and that is what's happened, whilst I was in hospital, they contacted the drug support team, ... they came to see me at the hospital and said, "When you get out, we'll make arrangements to get you a prescription and if you're serious about doing this, we'll offer you all the help that we can."  
(Rob)

Rob's account signifies a turning point in his health that is often characterised as rock bottom or a 'drastic' event that ushers people into thinking about making changes to unhealthy behaviours. It is often the case that in order to succeed, help is needed from health care services. The above excerpt reflects effective integrated care, in that the hospital were able to recognise this as an opportunity for Rob to receive help, contact the drug support team, and begin to put plans in place for Rob once he was able to be discharged. This seemed to be helpful for Rob as, further in his interview, he talked about making some key changes regarding his health:

I don't want to have a sell-by date or an expiry date on me, I want to be able to just carry on. But then you've got to be a realist about it, it's a pretty savage situation, my heart is in a mess but as I said, I'm toeing the line, doing everything I can, my diet, I'm looking after my diet, I'm in the process of stopping smoking fully.

(Rob)

In the above excerpt, it is clear that Rob was struggling to come to terms with his 'savage situation' and although he was being a 'realist' he was also willing to 'toe the line' regarding his health. Rob was the only participant we interviewed who had initiated changes to his drug use as a direct result of his diagnosis. It seemed that at this point in his life, the diagnosis of heart failure served as a catalyst for change, as for Rob, not having a 'sell-by date or an expiry date on me' was motivation for him to lead a healthier lifestyle and he was, at the time of the interview, receiving a methadone prescription. This could have been in part, due to the effective joined up working of the hospital and the local drug services. However, disappointingly for Rob, the follow-up care was less effective which left Rob frustrated and less motivated to make the necessary changes:

I had a home visit, they even come to my home because they've seen what state I've arrived there in sometimes short of breath, looking sick ... and the doctor came to visit me one day ... and part of the conversation was how do I feel about a possible transition onto [new opiate treatment drug] and I said "Yes, I'll look at that" as the next progressive step in my treatment programme ... and it was 'That's okay, fine, we can talk about it another day' ... on the Friday I picked up my prescription, methadone on a daily basis ... and the pharmacist informed me that my prescription had been stopped and would be starting this [new drug name] on Monday ... I was infuriated ... I thought to myself, how hard is it really to get somebody to sign something to say 'I agree to this transition and I'm fully aware that this procedure will take place and start on' ... one paragraph, all bases are covered, everybody's in the loop, knows what's going on.

(Rob)

After Rob had got in touch with his key worker, he was able to request that his original prescription be reinstated. He was again asked if he wanted to try the new drugs to which he said '*No, I don't feel well enough to be doing something like that at the moment.*' This could be considered a lost opportunity as Rob's experience of having his script removed without being consulted appears to have resulted in low motivation to try new medication. Nigel, on the other hand, had made some changes to his past drug taking through treatment, yet was aware that his smoking was still putting him at risk for further lung damage:

Like I said I've been smoking since the age of 11, I'm a diagnosed diabetic, stage 2 tablets, metformin, I've got emphysema but they don't call it that now, they call it OC .. [INT: **COPD?**] That's it, I've got that and that's through not only smoking from the age of 11 but ... I never injected when I were using heroin, I smoked all the time, all them years and it's done irreparable damage to my lungs and my chest and I'm still smoking now and they told me ten years ago that my lungs had gone a third and if I

didn't give up, it was only going to get worse ... and I haven't stopped.  
Obviously I've stopped smoking drugs but ...so I have tablets for high blood pressure, I have Valium for when I get stressed out ... but I'm clean.  
(Nigel)

Interestingly, even though Nigel had several chronic physical health conditions, and was fully aware of the 'irreparable damage' to his lungs and chest, he ended his summary above by stating that he was 'clean'. This positioning speaks to our integrated theme of 'carrying a substance use identity' as Nigel positions himself as a good person who 'never injected when I were using heroin' and had 'stopped smoking drugs'. Indeed, whilst under the care of his local substance use team, Nigel said that his key worker never asked him about his physical health and was just satisfied with his clean urine samples and ongoing substitute prescription. Conversely, his GP and diabetes nurse never asked him about his drug use. This seems to be one example where health care services need to have a better joined up focus that speaks to effective and holistic ways of working. Being 'clean' and passing urine tests enables Nigel to be positioned as a good patient in the drug treatment setting, as he was no longer using illicit drugs. However, this separation appears to ignore the complexities of his wider illness regarding smoking, perhaps because smoking was not considered as part of his drug treatment programme.

Rob and Nigel's accounts provide examples of how motivation to change behaviour can be influenced by the way in which it is managed from a health care perspective. Moving to new drugs or other ways of coping can be immensely challenging and concerning even for those who are contemplating change. Rob's example reflects poor service communication that consequently led Rob to experience frustration, anxiety and low motivation to change. Nigel was able to maintain the 'good patient' through passing urine tests and remaining 'clean' yet his additional significant health conditions were able to be separated out, perhaps detrimental to his overall care.

Particularly for people at this time in their lives who are coming to terms with an end of life diagnosis, any attempts to make positive changes to their substance use will be especially challenging. However, it can also be difficult for those who have made significant and positive changes to their problematic substance use to find themselves now having to come to terms with an end of life diagnosis. For example, Richard described the irony of getting 'clean' and 'really healthy' only to now have to take medication for his cancer:

RICHARD: Yeah, I've been involved in the drug culture whatever you want to call it.

Int: And there is still some use now?

RICHARD: Well only through my medicine I'm using now, for my cancer, which is ironic because I got clean and really healthy and then got some cancer now and a bunch of crap.

Richard's excerpt above exemplifies further the psychological challenges of coming to terms with an end of life diagnosis when there is a previous history of substance misuse. Indeed, the accounts presented within this theme give a real sense of the diverse and complex situations that can arise when dealing with both problematic substance use and end of life care.

### **T2.3 Summary: the need to improve the recognition of end of life care for people with substance use problems**

At the time of the interviews, participants were experiencing a range of clinical complexities and had varied past/present substance misuse problems, which were likely to impact on their existing considerable health issues. Considering the complexity of the nexus that encompasses end of life and substance use is challenging in many ways and not least for those who are having to psychologically adjust to end of life alongside feelings of guilt and shame around their past behaviour. Mundt-Leach (2016) reported that there is a need to improve recognition rates of end of life care for people with substance use challenges, in order to improve their overall care experiences. In this current sample, the mean age was 54 years (range of 38-71) and eight of the participants were aged 55 or over. MacGregor (2014) proposed that older drug and alcohol service users require different social and recovery needs in comparison with younger people. MacGregor (2014) suggested that this was because they are likely to have developed significant illnesses, have become more isolated and, as we have identified in Theme 1, are worried about experiencing stigma as a current or former addict. Therefore, potential recovery activities and any focus on positive behaviour change are perhaps not always realistic for older people requiring end of life care. Nevertheless, it is important to be able to find spaces where such current or past behaviours can be acknowledged, recognising that there is often associated guilt, shame and regret for people with substance use problems that can impact on their overall experience of care.

Moreover, an important note to make from this theme is that none of the participants increased (or returned to) using substances as a result of knowing about their health condition. There may of course, be many people who do increase or return to substance use as a response to their end of life condition and that we simply did not manage to speak to them. Nevertheless, contrary to how many people would expect those with substance use problems to react, in this particular sample it appears that none of the participants turned to alcohol or drugs to alleviate their emotional state.

## **Theme 3: End of Life Communication**

Woo, Maytal and Stern (2006) maintain that end-of-life care is optimised when approached as a thoughtful collaboration between the individual, family, friends and their treatment teams. According to Kennedy *et al*, (2014) identifying that a person may be at the end of life stages of an illness is a vital first step to planning and delivering optimal care. When asked about such experiences during the interviews, the majority of the participants presented their experiences in narrative accounts based on a series of events, which they considered important to tell when making connections to good or bad experiences.

### **T3.1 Negative experiences of diagnosis – poor communication in acute settings**

Acute hospital settings are reported to play a significant role in palliative care (Robinson, Gott and Ingleton, 2014). However, from the interviews conducted, it was clear that for people who were under hospital care, their experience of communication of end of life diagnosis was very poor. For example, Rob became aware of his diagnosis through a nurse suggesting that he consider visiting a hospice:



Six months later they told me about this place (hospice) and said “how do you feel about going there?” ... I was scratching my head thinking, “why do I need to go to a hospice?” ... the nurse explained, she said you know you’re very ill?” and I’ve flippantly remarked, “no shit” ... my heart is working at 14%, I know I’m ill”, she went, “no you’re really ill”, she went, “you could have as little as a year to three years to live.”

And later...

I had this conversation with possibly half a dozen people at the hospital and at no time did anybody ever say, “The likelihood of you actually being here in ten years is next to zero”. ‘It came across as almost flippantly mentioned but I think it was more a case of I think she presumed that I already knew.

(Rob)

Rob, up to this point had not been informed about the severity of his heart condition, and was clearly confused as to why hospice care was being suggested. His further frustrations that there had been no earlier discussions with anyone at the hospital about his prognosis, clearly led to a very poor experience where, ultimately, at the time of his diagnosis, he was on his own, confused and frustrated with how the nurse had “flippantly mentioned” he was “really ill” . Rob’s experience suggests a need for better multidisciplinary communication to avoid presumptions that patients have been informed of their condition. Similar to Rob, Susan was also on her own and was frustrated that she had not been informed earlier that there was considerable lung damage. Susan was further convinced that if she had not seen the X-rays during a doctor’s appointment, she would not have been told about her condition:

SUSAN: It wasn’t really the doctors who told me how bad I was, I don't know , if I hadn’t have said anything I really don't know whether the doctors would have said anything to me and what happened, it was in the hospital and the doctor was looking at an X-ray, a chest X-ray and he had it on the screen and he leaned over to do something and I happened to look at the screen and I saw for my own eyes, just how bad it was in my lungs and er, and I mentioned it to the doctor, I don’t remember what I said to him didn’t even really ... when I looked I could see I had very little lung space left on the X-ray, it’s like cloudy shadowy and then just this little bit and I said “I suppose I’d better start telling my family how bad it is because I’ve seen it for myself now” and he said “yeah” and that made me think, was he ever going to tell me or not? Maybe I did wrong in saying that I’d seen, I don't know.

INT: What had the doctors been saying to you up to that point?

SUSAN: I’d been in so many times with it and they were just saying, “You’ve got to stop smoking.” This is the main thing they kept saying to me, “Stop smoking.” I’d been in nine times, one of those was for a stroke, for four and a half weeks and the other eight was with my chest and it was pneumonia.

And later...

But I couldn't keep my mouth closed, I wanted to know because I'd seen, I think if I hadn't have seen that, I wouldn't have even said anything but because I saw that, I did and I truly believe that he probably would not have told me ...

(Susan)

Although he had suffered a variety of health conditions over the years, Daniel felt that frank 'long-term' conversations about his health should have started earlier:

DANIEL: Well it's just got worse, I mean it's got three times as big [liver] and it causes all kinds of problems. If your liver can't deal with it, your brain will deal with it and your brain wasn't made to deal with everything life chucks at it. I'm on all kinds of pills, and the doctor would never say what I should have been hearing off of the doctors.

INT: What kind of things were they saying to you then?

DANIEL: Well they were skirting round the issue, they were just saying what they could do that day. You know, there's never a long-term thing, and I'm one of them that wants to know this, that and the other.

INT: You felt almost like they were dodging your questions when you were asked?

DANIEL: No, I don't ask the questions, but they weren't forthcoming. I mean they could have said, "you're going to die in the next ten years because of what you've done. Oh and by the way if you carry on drinking you'll not get the next five years." They could have said that.

Similarly Barbara described being 'absolutely shocked' at hearing that she had stage 4 liver failure and was frustrated that she was not able to act on her diagnosis sooner:

I was demanding liver function tests from my doctor back in 2016 because I wasn't being called up, I went years ago, from when I was discharged in 2010 and I had no care whatsoever and it's only me demanding blood tests, that I was then told, "This isn't right" and it was then at that point in November last year that I demanded to be put into the [hospital] and I'm glad I did because I wouldn't have known I was at end stage, I wouldn't have known anything about care, about the diet that I've got to be on, what to do and what not to do.

And later when asked about her diagnosis Barbara explained that she spoke to the 'top dog of the liver unit':

She said "Okay, I know what we're going to do now, we'll do a fibro scan." So she got this machine ... and put it onto the liver ... she says "Oh you've got, your score is 27 which means that you've got stage F4 end stage liver disease." And I looked at my sister and my sister looked at me and I went "Oh." To be honest I wasn't expecting that because I thought I was quite healthy ... being told I'd got that, I was thinking, "How long have I had this?" If I hadn't have pushed my doctor in November, myself I wouldn't

know! As I said to you, knowledge is power and you have to push forward yourself to get anything. I was in shock, I was absolutely shocked to be told I'd got end stage liver disease because I felt so well.  
(Barbara)

In addition, Gill described confusion and misinformation about the process leading up to her diagnosis and perhaps if she had been a little better prepared, would not have ended up on her own to take in the news that she had lung cancer:

I went to the doctors and I told her about it. I said, "Doctor this, it's not the blood what I'm bothered about, it's me bloody shoulder what's killing me." She said "Now look, sort your shoulder out first, go for X-rays and then we'll sort your shoulder out." So anyway, they came back and there was a shadow on me lung. So they sent me to [hospital]. Anyway the results came back which I thought ... everyone thought it was funny ... I got a letter to see the specialist doctor at [hospital] and apparently what was supposed to have happened, my doctor was supposed to get me an appointment the day before to tell me all about what was going to happen what this doctor said. But I didn't know, so I went ... he was a nice fella ... anyway I sat down and he says to me, "Are you by yourself?" I said "Yeah." He said, "Do you know what you're here for?" I said "Yeah, I've just come for me results of me scan." "No" he said "What do you know?" I said, "I don't know anything, but I've just come for my results." He said "Gill, you've got lung cancer." I nearly dropped dead, I didn't think anything.  
(Gill)

Barry was rejected for treatment/surgery by various health professionals that eventually caused distress, and it was only when he went back to his GP that he was able to get help to raise it with his family through sending a letter:

The big thing , I've got an aneurism and it's on my main artery, I seen two consultants, seen the first one was going to put stents in my groin, then he decided that he couldn't do that, he'd like a second opinion. I seen another consultant who was going to open my chest to do it that way and he said, "I can't do that", and when I asked him why, he said, "Because you won't pull through it!" I thought "Charming chap" [laughs]. So then I had to go and see an anaesthetist, he took one look at me and he could tell the way I was breathing, he said "No way." So this is the thing now that it's really getting me down, I said to my GP how much it is affecting me, so the GP wrote a letter for my two sons and my daughter to read, for them to choose and on the letter it said that if I give the consultants the go ahead "It's not a very good chance your dad will pull through it" or "Shall we leave it as it is?" So we all sat round the table ... Any road we decided to leave be.  
(Barry)

Peter was with his brother at the time he was informed that he had liver failure, However, Peter was largely ignored during the conversation:

I didn't know what it was. Then the doctor came to see me but my brother was there so he weren't talking to me, he was talking to my brother rather than me. I said, "What's he say?" he said "Your liver's gone, proper." That was it then.  
(Peter)

In all of the above accounts it was clear that during their treatment encounters, there was very little, if any opportunities to talk about end of life care. Indeed, for some, the diagnosis and/or prognosis was a surprise and not the result of a direct, targeted conversation that was intended or planned. The majority of the participants above felt that such conversations should have come earlier, that for some would have perhaps helped with their care planning.

Although the above accounts may be similar for others experiencing an end of life diagnosis and thus not specific to substance use issues, it is argued that people with substance use problems are more likely to be vulnerable to poor communication. Indeed, interview data from friends families and carers (conducted as part of the wider current project) highlighted how, for many communication had broken down over the years leaving very little avenues to be able to talk about substance use problems (Yarwood et al., 2018).

### **T3.2 Communicating end of life to families and friends**

Communicating end of life to families and friends was difficult for many of the participants, particularly when the busyness of treatment reaches its limits. Richard and his wife described the treatment regime as being 'horrendous', yet still treatment was constructed as hope and 'something to hang on to'. It was only when all treatment avenues had been exhausted, that they were ushered into having conversations that they had previously managed to avoid:

RICHARD: It's really the last week has been horrendous for us to be honest with you, because having treatment, having, although the appointments and everything else was such a hassle and a drag, it really gave you some hope right, and that's kind of, last week was like, you know, we had the big hugs...

WIFE: It was just something to hang on to, more I think than hope, it was just, it was something there to hang onto, and then all of a sudden, that's gone and you're kind of, you flounder.  
(Richard and wife)

And the other day, [wife] and I had the discussion that we had been avoiding, which is funeral and the end, and it was the first time we'd talked about in any depth, and it was very emotional and what not.  
(Richard)

Having to tell family and friends was an additional worry for many of the participants. Indeed, it has been recognised that often there is a need to protect families and friends from the 'business of dying' (McKechnie and MacLeod, 2007). For example, Rob attempts to present a veneer of wellness to his friends as he perceives they will feel uncomfortable with his current health condition:

A few of my friends are like that, just making sure that I'm alright and I can tell that it's cutting them up, it's a horrible situation to be in and I think they must feel awkward, they don't want to bring it up and then there's me being blasé and flippant about it.

(Rob)

Nevertheless, Rob talked about his son and feared for how he will cope:

INT: Have you talked to the people close to you about the kind of things you do want as things get towards the end?

ROB: Just coming closer to having a conversation about that sort of side of my life, my mum, I've spoke to about a few things but not my boy, I try to limit the amount of hardness of the situation.

INT: So it feels like a burden on him if you talked about it?

ROB: No I just don't want him being left upset, he's got enough on his plate to have to deal with when the shit does hit the fan, he's going to have a lot to say and have to do and I don't want him worrying about something that we've not spoke about and him thinking "what's my dad going to say?"

(Rob)

Similarly, Barry felt that his sister might not be able to cope with his illness and Therefore, did not 'want to worry her':

I've got a sister ... and we're very, very close ... she's disabled now because she had a bad stroke. But I love her to bits, she knows about the aneurism but we don't talk about it because she's got her own problems, I don't want to worry her.

(Barry)

For Susan there were worries about having to tell her son who had learning difficulties and lived with his father (who she described as bullying and emotionally abusive to her). Susan struggled to find help and advice regarding how to go about letting her son know about her health condition:

I've already told the boys, I didn't know how I was going to and I didn't plan it, all I thought was "I'm going to have to tell them" because nobody else had said anything to me about it and I did, I wondered how I'm going to tell them, where will I tell them, will I get them in a group or will I tell them as I see them and then it won't seem so daunting? And that's what I did, I told my daughter first and then I told my son, [name], the 21, 22 year old now, I've not said anything to [son with learning difficulties] because I don't know ... whether it's the right thing to do, the wrong thing to do but if I do say anything, what do I say? You know? And that was another reason that I wanted to let these social workers of [son with learning difficulties] know, so they could have a think about it, discuss it with [ex-husband] and then between us all, we could come up with a way to tell [son with learning difficulties] because at first, I thought maybe you don't tell him and it just happens but is that fair when everybody else knows? I don't think it is. I think maybe, there's got to be a way that they can, I might be wrong, I've

nobody to turn to, to ask about that. School break up Thursday so the chances now of talking to school are slim because that would have been another one I'd have brought in, I'd just like to have got people in that know about it, that have come across something like this before, that could maybe advise me but I met a dead end at that.

(Susan)

In trying to reach out to her son, Susan tried to get her son's social worker to help out – but this backfired when the social worker called her son's father instead:

I tried to ring the manager of [son with learning difficulties] social worker to tell him what position I'm in now, not say anything to [son with learning difficulties], just to inform them so if anything happened quickly, at least they'd got an idea that something, I'd said something and the social worker, instead of when he got the message to ring me, he rang [son with learning difficulties] dad, ... so his dad rang me and I haven't told [ex-husband] or the other boys yet and he's saying to me, "What are you doing ringing [son with learning difficulties] social worker", you're looking at a year down the line maybe, I said "actually, it's quite personal, it's not something that I want to tell you over the telephone" and I'd said to him weeks before, a few times I've said, "I need to sit down with you and the boys and talk to you about something", so I said to him, "that's why I kept saying I want to sit down with you and the boys and tell you what's going on", "tell me now while we're on the phone", I said "I'm certainly not telling you over the phone like this, I'm not".

(Susan)

Susan also had additional worries of telling friends, and she was particularly worried about having to get in touch with her AA sponsor:

But I feel that I've had to, well I have had to tell people myself and I'm so annoyed because there's two people that I haven't told and it's really, really disgusting of me not to tell them but I'm frightened of telling them. One is my sponsor because even though it's all them years ago, I've kept my sponsor because he is so worldly ... he would probably say to me "ring me every morning" ... and another one is, and he'll say this straight out to me, fear, I'm full of fear when I'm telling him, this other person. So I know when I've got all these different sort of behaviours going on in myself because he's taught me to know that something's not right, I'll ring him up, about anything and he'll give me good feedback. So yeah, fear as well.

(Susan)

Such struggles to be able to tell friends and family can have the potential to leave a person feeling isolated and lonely. For people who have past histories of problematic substance use 'carrying a substance use identity' can add to the complexities of restoring relationships and knowing how and when to say goodbye.

### **T3.3 Summary: understanding the implications of communication**

Communication is important regarding all aspects of patient care. It has been reported that 'more than half of NHS complaints are associated with care of the dying' (Sleeman, 2013: 197) with many of the complaints being focused on information and communication. Interestingly and somewhat concerning, is a report by the Care Quality Commission (2016) which highlighted how health professionals often find it difficult to identify the end of life phase, particularly if it is not a diagnosis of cancer. Indeed, Kennedy et al. (2014) found that health professionals were more likely to regard cancer as a terminal illness than other conditions. Fear of getting it wrong was also reported as a reason for GPs not always identifying end of life diagnosis at an early stage. The Care Quality Commission (2016) report goes on to suggest that there is a shift needed to move the focus away from the last 12 months of life, to conversations about care needs and preferences during the last phases of people's lives. This shift speaks to communication issues that have arisen in this study, as we found that the majority of participants did not feel fully informed about their condition. For those people who are not in regular contact with health care services, there is a need to look at ways in which early conversations can occur in order to avoid unnecessary distress for the patient and their loved ones. Having to communicate their prognosis to friends and family was an additional burden for many of the participants.

In relation to considerations for people with substance use problems, receiving an end of life diagnosis is arguably more detrimental because of a variety of additional factors including:

- Health professionals may not be communicating well about any aspect of their health condition because of stigma;
- People with substance use problems may have particular challenges in hearing the message – because of anticipating discrimination/shutting down from judgemental sources of authority; memory/capacity problems;
- More likely to have limited family/carers around them to help absorb the information; and
- The likelihood of being very close to death and needing to make decisions/plans quite rapidly due to people with substance use problems being more likely to present late.

### **Theme 4: Adjusting to end of life and end of life care needs**

Witham et al. (2018) highlighted the rise in the number of older drug users and how this is likely to result in the increase of death from non-drug related conditions. Therefore, care places such as hospices may be increasingly expected to take on cases that fall outside cancer related illnesses. This theme offers further insight into how participants adjusted to their end of life condition and how their care needs were met.

#### **T4.1 Offering appropriate health spaces**

Both of the hospices involved in the current research project offered 'day therapy' for example, where people had the opportunity to engage in a variety of therapies that enabled individuals to enjoy a change of environment and scenery. The Day Therapy also aimed to bring people together in a 'safe and relaxing environment' (taken from one of the hospice websites) who were experiencing similar health conditions. Rob for example, enjoyed the 16 week course as it gave him something consistent in his life:

I enjoy coming in, so if I was asked, they've already given me a little extension [laughs] ... but it's got to come to an end soon and when it does ... the course finishes in 16 weeks ... so just as you're getting built up and enjoying it and getting the school of thought, something consistent in your life.

(Rob)

Like Rob above, for the majority of those interviewed in a hospice setting, there was no doubt that hospice experiences were more positive than hospital experiences of care. However, it was also clear that adjusting to this new space was difficult for some. Rob, for example talked about feeling 'too young' and in a 'minority' to be in a hospice surrounded by predominantly older people:

I'm still a little bit ... I don't know, sort of a bit stage-fright-ish type thing. I still feel that I'm almost on display, the new guy and also then there's the age factor ... there's only one other person here that's even remotely near my age and just in general, being in new surroundings ... it's just a very surreal and strange environment isn't it?... Like they have the chair-exercise, I'm dropping to bits, I'm knackered but if they asked me to stand up and do some chair lunges .. I could probably do them, so sitting on a chair like a little old man ... it makes me feel strange ... It comes back to that I feel almost too young to be here, but obviously there's no age limit to illness but I think ... yes definitely in a minority. It would be interesting to see if they could sort of work something maybe for younger people.

(Rob)

Above, Rob is trying to make the necessary adjustments in order to cope with his current health condition and being in the hospice has been part of that transition. However, Rob appears to be conflicted with being the new 'guy' who is 'too young to be here' and the realisation that he is limited in his abilities and needs help. Being in the hospice and witnessing the degree of frailty that surrounds him positions him as an outsider and 'makes him feel strange' to think of himself as 'a little old man'. Rob seems to be faced with the reality that his frailty is an inevitable part of his condition. It is Therefore, important to consider the impact of belongingness in such surroundings and the possibility of tailoring services for more people like Rob who are likely to be referred in the future. Similarly Nicola had been diagnosed with MS and was now in a nursing home. It took Nicola six months to accept that she needed help and that the nursing home could provide this, however, she was frustrated that the nurses did not seem to acknowledge that she was considerably younger than the 'elderly people' there:

It must have been a good six months before I was accepting of being in somewhere like this and a couple of the nurses, they weren't nice to me ... I've met some lovely people here, you know, elderly people, and I like elderly people, they don't bother me, but what those nurses fail to remember is that I am 58 not 98, and I, I'm not being awful saying that because when you get older you are prone to dementia and you do lose your mind and not think straight.

(Nicola)



Therefore, both Rob and Nicola struggled to achieve a sense of belonging with the hospice/care setting, yet ultimately, through their health conditions had to accept the inevitability of needing to be there to receive appropriate care. Such feelings of frustration and lack of control clearly impact on optimal experiences of care. For people with substance use problems, it may be difficult to talk about their feelings and experiences openly due to avoidance of experiencing shame and stigma around past or present substance use behaviour; therefore, this could be explicitly encouraged by health professionals to ensure smoother adjustments are made towards hospice and other care settings.

Where a sense of belonging is achieved, the personal experience can bring about many positive psychological benefits, not least a sense of shared identity that can combat loneliness. Nigel, for example, was recruited from a community men's group that had been set up specifically for (ex)substance using men. Through the men's group, Nigel was able to engage in 'adult' conversations and make connections to other men through common interests such as football:

There's another guy, [friend] and he's a great lad, fantastic lad, I went last week and he couldn't make it and it was only me and [friend] there but it was adult, he's older than me and really enjoyed just one on one talking with another guy my age, not about drugs, not about drink, because he's an alcoholic, I'm a narcie [slang for someone who takes opiates/narcotics] , ... but that didn't, we started talking football ... so I look forward to going actually.  
(Nigel)

Moreover, Nigel explained further how he benefits from being part of the group as he is able to identify and share his health concerns with other members who have similar issues:

Talking about this [friend], he's got what I've got basically, with the emphysema and he's worse than me, am I right? [Yeah] but we associate with each other because we have got that in common and when he tells his stories, I can relate to them, you know what I mean because other people might not in the group cause they haven't got emphysema but I can and when I tell mine, he'll get onto them and say "I'm like that all the fucking time" do you know what I mean?  
(Nigel)

Nigel is able to experience a better sense of belonging as he socially affiliates with other men who are a similar age and share similar health experiences. Moreover, the men's group enabled Nigel to have a space in which he could talk about his problems, whilst keeping his masculinity intact. Being able to identify with others, perhaps initially through similarities such as age and gender may be more likely to help support people with substance use problems who can come from isolated backgrounds. Therefore, considering appropriate health spaces where people with substance use problems at the end of life who are also more likely to have other related illnesses is important to consider when developing service provision.

## **T4.2 Fear of dying and being alone**

It is perhaps inevitable that once a diagnosis has been made it may bring a person closer to thoughts about death and dying. If it is something that is feared then it is probably less likely that this would be discussed with others. Dying can elicit a range of difficult emotions, not least fear of the dying process, and the fear of dying alone. For example Susan was worried about the pain and dying alone:

Just hope that it's not going to be painful but we don't know. I said to my daughter I don't want to die on my own.  
(Susan)

Although being at home is often a preferred choice for palliative care, hospices can decrease loneliness and the fear of dying alone, for example Gill was happy to remain in the hospice as it made her feel more secure and less lonely:

I think at the moment I am quite satisfied to be in here, because if they sent me home I'd be frightened to death I know I would.  
(Gill)

They are a lifeline to a lot of people, but like the phone, if I got frightened or someone to talk to, I can ring numbers up and there's always somebody at the end of that phone. It makes a big difference, because you're never there alone.  
(Gill)

Dying pain free is also a very common fear for people who are adjusting and facing impending death. Steven shared his concerns about the dying process and was worried about experiencing pain whilst not being able to speak:

I know I'm going to go through some more pain, the pain's going to get worse and I know that for a fact and I might not even be able to speak, I can be just like a zombie or just out of it, getting drugged up and then pass away. That's the most thing that I'm afraid of, just hoping that I can help anyone out that can listen to this.  
(Steven)

Later Steven talked about how he had difficulty sleeping (he had sleep apnoea) and how he did not want to be alone at night, Therefore, his mum and sister tried to stay with him in the hospice as much as they could:

INT: Is it two sisters you've got?  
STEVEN: Yeah ... The younger one stayed here last night, they let my family stay because I can't stay on my own because I get frightened of a night. You know, in case something happens in the night.

Susan, who has COPD, was describing her current condition regarding her health and there were many including rheumatoid and fibromyalgia pain where 'one thing's led to another'. Susan did briefly reflect on whether she would like to know what death would be like:

So you know, it can start with maybe one or two things but what they lead to, nobody knows, I've never ... I am today where I am and I quite often sit and think about ... if I'm not here, what's it going to be like when I'm not here? I won't know what it's like when I'm not here, I won't know when it's going to happen and I think would I like to know? Probably not. Probably not.

(Susan)

Susan appears to be experiencing some ambivalence between wanting to know something about what her death experience may be like, with 'probably not' wanting to know. The above excerpt signifies a closing down of such thoughts around dying, perhaps because it may lead to feelings of anxiety. There was no mention of any discussions with health care professionals about death itself and more of a sense of Susan alone with her thoughts; perhaps having opportunities to talk about 'when it's going to happen' may have helped Susan in some way.

#### **T4.3 Summary: the challenges of care needs for people with substance use problems at the end of life: what should we consider?**

Penman and Ellis (2015) propose that healthcare professionals need to have appropriate knowledge and skills to be able to provide emotional care, and allay particular fears associated with the process of dying. In relation to this research project, the shame, guilt and secrecy often associated with problematic substance use can result in a tendency to keep experiences, thoughts and feelings hidden. Indeed, none of the participants interviewed spoke about engaging in discussions about the dying process or their associated fears with hospice staff, nurses or other health care providers. This may be due to the way in which questions were asked at the time of the interview, however, common across all interviews was how fear was articulated, yet there was no engagement that worked towards allaying such fears. This is arguably an important issue for people with substance use problems who are adjusting to end of life, as often many are experiencing, or have experienced, loneliness and isolation and may fear 'opening up' to health professions about their thoughts and feelings. It is here that the integrated theme of 'carrying a substance user identity' again emerges as past experiences may have left individuals with limited resources with which to enable 'therapeutic' discussions to occur due to mistrust of health services and secrecy around past behaviours. It may also be that what is currently offered in terms of emotional support works poorly for people with experience of problematic substance use who may be used to being quite secretive over their health, and are not well versed in having to rely on health practitioners to help them. Indeed, contrary to what health practitioners may expect (about 'demanding/manipulative patients'), they actually often minimise their needs.

In considering the above, it is clear that there are key emergent issues from this particular theme that could be translated into training and guidance for health practitioners working in the field of substance use and end of life. In particular, training and guidance around identity, shame and stigma in relation to substance use may help to aid better care experiences. Certainly helping people to overcome feelings of guilt/self-blame about 'brining their premature death on themselves' may be especially important if other family support networks have broken down for them.

For wider commissioning and policy decisions, considering health care spaces may help to combat loneliness and enhance belonging for people with substance use problems and life limiting conditions.

### **Theme 5: Managing the treatment and care experience: the need for helpful, holistic, and humanised care**

Overall experiences of care are likely to vary and much may depend on the psychological, physical, social and spiritual needs of the person and how it relates to their condition or 'illness trajectory' (Murray et al. 200). In addition, the different health care settings and cultural 'ethos' of such settings will also impact upon the kind of encounter experienced. This final theme draws together some of the ways in which the participants experienced and managed their overall care and treatment in relation to end of life care and the need for helpful, holistic and humanised care.

#### **T5.1 'Just a number': hospital experiences**

When listening to the accounts of treatment experiences for their health conditions, it was difficult not to see how stigma still shapes the way in which people understand and respond to individuals with substance use problems. Throughout this analysis, the integrated theme of 'carrying a substance use identity' has underpinned much of our understanding of the experiences of people with substance use problems, and this was again evident in relation to acute/medical treatment settings. For example, Peter talked about feeling 'just as though I am a number' when visiting the hospital:

When I'm in hospital, it's just as though I'm a number, do you know what I mean? ... I need help.  
(Peter)

Furthermore, there were other accounts where, again in the hospital setting, the health care experience was described as dehumanising. For example, Barbara felt that she was not seen as an individual person with an important back story, rather 'another person who just drank':

[Gastroenterologist] he's treated me as another person who just drank, he didn't know my background, he didn't know I was abused mentally and physically by my husband ... I was beaten, he didn't know that, he just thought a six stone alcoholic and that is all he could see because he had no delving into my past.  
(Barbara)

They've never really said to me, "How did you start drinking in 2008?" It was just a bit of a background that they were after.  
(Barbara)

Hall (2000) talks about such encounters as not getting to the 'heart of the matter' where professionals do not take the time to understand the person in his or her context. Indeed, the need for more holistic approaches to care is often the part that is absent in busy health care settings due to time constraints (Murray, 2004). When a person feels judged as Barbara describes above, understandably the impact can lead people to disengage with services.

Furthermore, Steven described a particular encounter at the hospital where he 'went through a bad time' due to suffering from liver failure. Liver failure can affect brain functioning leading to psychotic episodes known as hepatic encephalopathy (Felipo, 2013). However, in Steven's excerpt below, health care professionals' knowledge and understanding of some of the effects of liver failure appear very limited:

INT: How does [hospice] compare to being in hospital?

STEVEN: To tell you the truth, I would never, ever go back in a hospital, it would have to be somewhere like this or at home.

INT: Why is that?

STEVEN: Because I went through a bad time in ... just like I were in there rotting, I did one thing wrong which wasn't my fault, toxins gone to my head, must have been off my liver, early hours one morning I went crackers ... a bit of singing, swearing at patients, throwing chairs at doctors and all this and that's not like me at all. Some of the staff was dead funny about it but I couldn't help it, I didn't even know what was going on and I'd old my hands up if I knew what was going on and said "right, I did know what was going on" but I didn't. toxins had gone to my head and they was walking past every time I rang the buzzer, wouldn't come in, half of them and last time I went into the same ward, just after Christmas, I overheard what one of them said when I went in, she walked past and she went "oh fucking hell, he's here". That was disgusting, I'd never go back to that place.

Peter, Barbara and Steven's accounts above reflect what Todres, Galvin and Holloway (2009:73) would describe as a 'loss of personal journey' where 'health care practitioners do not pay sufficient attention to the history and future possibility of a person's life'. Thus, as exemplified above, the 'snap shot' consultation or hospital encounter are separated from the person's social context and, therefore, treated as a 'case' rather than a person with a history and a 'back story'. Thus, Todres, Galvin and Holloway (2009) have called for a 'humanization of healthcare' that will importantly combat such negative and dehumanised experiences.

### **T5.2 Positive experiences of care: hospice as refuge and humanised care**

In contrast, the hospice experience was characterised as a refuge from earlier and often 'horrific' or indignant hospital experiences. Although the hospice was perceived as the 'end of the road' in terms of its function, the 'business' of treatment was replaced by an acceptance of what was ahead. The hospice appeared to offer a space for individuals to let go and have others involved in more day-to-day activities such as making a 'brew'. It was evident in the interviews that in contrast to Theme 1, preservation of identity was not highlighted as problematic in this particular space – if highlighted at all. Indeed, the opposite was expressed by those who were receiving care at the hospice at the time of the interviews:

I think it's absolutely brilliant, absolutely fantastic. I can ask the nurses anything and if they talk about certain terms, I just say, "Can you say that in black and white?" They tell me everything and it's all right, it is. (Gill)

I've been in here nearly two and a half months now so it's been the best help I've ever had in my life, they do everything for me. I can ring the bell

at any early hours of the morning, if I can't get up, you know, they'll get me a drink or make me a brew ... if you come to this place, you'll know what I mean, you wouldn't need anything else and you get to meet people, friendly people, some with the same problems as what I've got, some are in here for different stuff but it's nice and it's nice and friendly, it's just ... a beautiful place. I'd recommend anybody ... sorry that morphine is making me a bit drowsy. (Steven)

Steven's experience of the hospice is positive as he describes feeling valued, where staff at the hospice make time for him and are able to attend to his needs in a way that matters for him. The way in which the hospice approached 'person-centred' care seemed to be very much aligned with how Steven wanted to have a relationship with his carers – he wanted to (and did) express his appreciation by buying biscuits and chocolates for them. Interestingly Steven had also done this previously for the hospital staff – but regretted having bothered because of the poor care he received (as outlined earlier). Indeed, as part of the wider current end of life research project, Steven's experience relates to a comment from an informal telephone conversation with a homelessness worker who highlighted that the people she worked with often felt the most cared for and the most care they had ever had as they approached death.

It is suggested that one of the ways in which the hospices effectively delivered good care for people such as Steven and Gill above is the way in which they are able to hold on to some sense of normalcy. Barbara, for example talked about the value of the hospice's befriending service and described the need to feel 'normal':

It's good to have the knowledge and it's good to have the care and the support but it's really important to have normality, whatever you call normality, to be normal ...I'd just love a normal life ... to do things which I can't, I'm sort of stuck but I know where I am and I do need some support in the home. (Barbara)

Thus, the hospice and its services enable the person to be accepted as 'normal' or at the very least, the person is ascribed an identity that underpins the person rather than the stigmatising characteristic, again an approach that speaks to humanised and holistic care. Moreover, hospice care appeared to be very much about what can make people's experience better and more comfortable in the 'here and now', which perhaps makes individuals much less vulnerable to stigmatised attitudes regarding substance use.

### **T5.3 Balancing the need for care: building trust and adjusting to support**

What was also interesting to note in terms of care experiences was how participants negotiated when to engage with services, and when to ask for help and yet remain in a position of relative autonomy. It was identified in Theme 1 of this research analysis that there was a need to build trust between the individual and health care practitioners in the context of feeling stigmatised and marginalised by poor health services. This was an important and challenging step for people with a history of substance use problems who find themselves needing help. Therefore, for many people there is a new and potentially difficult negotiation to be developed. For example, Richard talked about getting the balance right which wasn't always easy:

I think the smart move of these sorts of systems, these organisations ... they don't want to be in your face. They gauge very well how much help you ask for - and we didn't, we were quite independent. We thought we'll manage this for as long as we can ... so they backed off. And there were moments where it was like: "Ooh how dare they back off." Kind of thing, but you know, or "Where the hell are they? What a rotten service."  
(Richard)

However, both Richard and his wife went on to say how they had managed the balance between needing to be independent, but also recognising that they needed care. It was here that the integrated theme of substance user identity was again evident in people's experiences of balancing/negotiating care. Building up trust after years of feeling marginalised and stigmatised was very apparent in many of the accounts given. Indeed, Richard and his wife went on to reflect such feelings:

RICHARD: I always feel like my pants are hanging out my arse, do you know what I mean?

WIFE: Your arse, hanging out your pants? [laughing]

RICHARD: My pants are hanging, do you know what I mean, wherever I go, whatever stuff I do I suppose that's it, just a bottom line there's an element of guilt or something there, just constantly or you know ... and it's a fact thing ... it's like where I've been, what I've done, so and so forth you know and that's it.

(Richard and wife)

At the time of the interviews six out of the eleven participants were no longer using substances. The interviews appeared to provide a space where participants reflected on their past behaviour when coming to terms with their current illness. For example, Richard described himself as a past 'junkie' who had managed to get 'clean' at various points in his life. Richard was keen to present himself as 'fit' and Therefore, able to cope with the strong doses of drugs used to fight his cancer. However, there were 'tough times' relating to his past behaviour and his concerns around taking pain medication:

INT: But then, possibly also, I don't know, able to tolerate a lot of drugs perhaps, it sounded as if at times you're use was quite serious and heavy, so your body is used to having a lot of toxins in it I guess?

RICHARD: I think so. Yeah, it was weird, yeah I also for quite some time resisted using any pain killers because of the association, and I was able to put up with a lot of pain which was ... [you didn't want any drugs at all, even prescribed?] no, no it was a real battle ... that was a tough time ... and [wife] said "look come on, and you're in a lot of pain. You're not a junkie anymore, you won't be just because", but it was a big battle that went on in my head, it was a real, it was a difficult thing, and I still feel guilty at times, and it's very, it's still difficult, it's really weird.

(Richard)

Richard has clearly 'battled' with the guilt and worry of returning to his 'junkie' identity if he were to take pain medication and to accept that he needed pain relief. Indeed, contrary to

many health professionals' fears about 'misuse of opioid painkillers', many ex-drug users may need encouragement to take what they need.

At the time of the interview with Peter it was clear that he was suffering from multiple health conditions including liver failure, cognitive difficulties and problems with his balance (resulting in frequent falls). Peter had a long history of problematic alcohol use, but had managed to stay sober for the past 11 months. He was struggling to work out all of his appointments and the specialists he was waiting to see. His care worker was also confused:

CARER: That one's actually the GET, that's the gastroenterology clinical team that would support [Peter] when he's in hospital, but this is more for the chest clinic, so the nurse practitioner but it's to do with the chest, so unless they're actually working in the chest clinic, this is confusing.

PETER: But I've never had nothing to do with my chest.

CARER: So it's just you go to the chest clinic but when you read it, they're quite confusing these, it's a nurse practitioner or another specialist in gastro, so it could be the liver specialist, it could actually be that.

(Peter and his Carer)

During the interview with Peter and his care worker there were over 10 different health care services/practitioners talked about who were involved in his overall care. These included; a liver specialist; liver specialist nurse; chest clinic; physiotherapy; Alcoholics Anonymous; carers; specialist in gastro; drug and alcohol services; GP; social worker; and an occupational therapist. At the point of the above excerpt, Peter and his carer were trying to understand where a letter for an appointment had come from and what it was about. Therefore, for Peter there was much confusion about his health care with what appeared to be very little joined up care work.

#### **T5.4 Summary: considering connections between end of life and substance use**

As identified in the previous theme, the way in which care needs were met depended to some extent on the particular setting. The hospice approach clearly differed from the acute setting in terms of the time afforded participants which clearly impacted on their experience. What has been interesting to note from this theme and throughout the analysis is that all the participants predominantly spoke about their end of life care rather than their substance use treatment experiences. This was in part due to some of the participants having not used substances for a long time, but for many it seemed clear that substance use services were not set up to pay attention to the end of life aspect of their condition. Indeed, substance use services are now framed and operate within a recovery model – where people get better. For our participants, this was not going to be the case. Therefore, much of the storytelling was centred around end of life care. In some cases, it is clear that better joined up working would have benefitted some of the participants as having single care pathways result in compartmentalised approaches that can leave a person frustrated or confused as exemplified by Peter's account above.



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## Conclusion and implications

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It was evident from this research strand that the people we had the privilege to speak to had varying capacities and resources to meet a complex of social needs and social roles. This was a challenging and ambitious project, evident in the complexity of our sample and the range of difficulties involved in each person's care. The storied accounts that were gathered enabled us to gain an 'insider' perspective to people's experiences and offered a framework for gaining a valuable understanding of participant's needs, hopes and fears at this particular point in their lives.

It is perhaps too easy to make broad generalisations about end of life care and end of life experiences for people who have substance use problems in an attempt to propose some idealised 'correct' way that care should be provided. Individual difference in experiences, illness and social relationships should be recognised as key in understanding how to best meet people's needs. Indeed, we propose that more work needs to be conducted that embraces the complexity of such issues, rather than any attempt at reductive thinking that can consequently minimise what is needed to support people appropriately and effectively. Nevertheless, from the research conducted and from the information gathered from people with experience of a life limiting illness linked to substance misuse, we were able to identify key patterns in the data from which important conclusions and recommendations were drawn.

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### Key conclusions

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- Our analysis revealed that talking about end of life and receiving an end of life diagnosis from health professionals was varied across the participants, However, for many this was described as suboptimal, and for some, an extremely frustrating and lonely experience.
- In line with existing literature on palliative care our findings appear to support the argument that diagnosis is important for those who are dying with life limiting illnesses other than cancer, and that cancer is linked to more explicit recognition that other illnesses are not afforded.
- Moreover, when life-limiting or end-of-life care is linked to problematic substance use, there appears to be a need for understanding some of the barriers to treatment and care, in particular feelings of shame and guilt relating to substance use behaviour past or present.
- Self-stigma and the anticipation of discrimination/negative attitudes of practitioners/carers could be having serious impact on health conditions and poor prognosis, particularly in relation to late presentation of illness to health services.
- Hospital and medical treatment/care experiences were described as considerably worse than hospice care due to the absence of humanistic care. It was found that care experiences in an acute hospital setting was directly related to 'active treatment' experiences and encounters that was in stark contrast to hospices where comfort, holistic and valued care was the focus.
- Hospice care was perceived as positive and a place to alleviate loneliness. This is particularly important for people with past or current problematic substance misuse as often they have previous experience of isolation.

## **Service delivery: the need for contextual, relational and holistic care**

Our research findings have the potential to challenge dominant discourses that surround people with substance use problems who are at the end of their lives, with a need to shift towards better recognition that they hold the same needs/desires and values as 'others' at this point in their lives. Indeed, how the participants in this study were regarded by others around them and, in particular, health care workers was important, and influenced levels of engagement. If central negative beliefs about past substance misuse identity can be met with compassion, correct knowledge of the person and basic core health needs, then the experience is more likely to be positive. It is also important to note that many of our conclusions are not necessarily new; issues around caring for people with substance misuse and understanding the role of shame, stigma and guilt in people's treatment encounters reflects a large body of existing literature. The same holds for arguments calling for more effective joined up working and improved holistic and humanistic care within the health setting. Therefore, in addition to further scaled-up research on this topic, there is a need to ensure that next steps move towards impacting on policy and practice that directly improves people's end of life care experiences. Further key service delivery implications include:

- A move away from a 'one size fits all' model that ignores contextual and personal circumstances that would aid or hinder health care.
- A need for better recognition of those with past or historic substance use who are at end of life and more effective joined up working with palliative care services and treatment agencies.
- An investigation into the role of substance use treatment agencies in relation to end of life care.
- More consideration of diverse, appropriate and aligned health spaces. For example age or gender related environments that enable better engagement for end of life care linked to substance use.
- A better understanding of the relationship(s) with drug and alcohol and end of life services and challenges to single-issue treatment pathways that appear problematic
- For some of the participants in this study, adjusting to end of life and end of life care in a hospice, meant having to balance an 'outsider identity' of not belonging with an 'insider identity' of needing care. Our data suggest that it is perhaps highly unlikely that either medical professionals or those using substances would consider hospices, as among the five hospice users, two had cancer and Therefore, had been referred into palliative care (pain management expertise), one had been referred by a heart failure nurse and two had self-referred.

## **Implications for policy and practice**

- Anticipation of discrimination and negative attitudes of practitioners and carers could be having serious influences on late presentation, Therefore, health care practice *still* requires more compassionate care training approaches in relation to working with people who have substance use problems. Practitioner attitudes and understanding identity more broadly that can feed into practitioner behaviour is required in order to improve service engagement.
- Professional identity may inhibit some medical professionals from talking about end of life, either because they consider it someone else's responsibility; do not want to

consider that they might not be able to 'save' their patient; or because they do not want to admit that they cannot be sure what the trajectory is for someone. Nevertheless, this research would argue that there is an important need to encourage consultants (especially hepatologists and gastroenterologists) to talk to people (and their families) about possible premature mortality.

- Support and guidance to help with the difficulties of communicating end of life to families/friends/carers/children.
- Flexibility in support/treatment, time, space and place require re-thinking in terms of adaptability and availability of services and an exploration of the role that the community could play.
- Better and more effective lines of communication regarding end of life/diagnosis/prognosis
- The need for health care services/individuals to be able to share pertinent information and allow flexible planning that is open to change for people at the end of life with complex health needs.
- The need to find ways to reach out to individuals at a community level in order to provide timely health care support. Combining a community recovery model could perhaps be beneficial here.

### **Implications for future research**

From the findings of this current research project, we would pose further questions for research:

- Are health care professionals ill-prepared for working with people who have substance misuse problems and do existing stereotypical views influence their approaches and encounters during treatment/healthcare processes? (Particularly regarding difficult conversation that include end of life care and substance use.)
- What are the barriers to effective end of life communication?
- What can hospital and medical practitioners learn from hospice approaches to end of life care? How can they share best practice, particularly in relation to the time differences afforded to such practices?
- What would a wider and larger sample of people with experience reveal in relation to a more diverse cultural and ethnic group?
- How can we engage the substance use sector in further work?
- How would a model of care developed by people with experience help to shape practice?

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## Appendix 1: Interview topic guide

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### **End of Life Care for people with alcohol and drug problems Topic Guide – PWEs**

#### **Interview preamble**

- Information sheet (Any questions?)
- Focus on your experiences and thoughts: tell your story in your own words
- Don't have to talk about anything that you don't feel comfortable discussing, so just say if there are any questions you don't want to answer.
- Let me know if you are unsure about any questions or want me to repeat them.
- We can stop the interview any time - just say if you need a break at any time.

#### **Consent form**

- Recording and confidentiality: limit to confidentiality if risk of harm to yourself or another
- Happy with everything so far? Any questions for me before we begin?

#### **Introductory questions**

1. [Referrer] put us in touch with each other: how did you first meet them?

#### **Help for alcohol/other drug problems**

As you know we're interested specifically in the experiences of people who use alcohol and drugs. I'd like to talk about that with you – are you OK to continue?

2. Can you tell me about your alcohol/drug use?
3. Have you had any involvement with substance use services?
4. Can you tell me about good practice that you've encountered? Are there things that have gone particularly well? Or anything you've struggled with?

One of the aims of this research is to make recommendations about how people who use alcohol/other drugs could be better cared for, so I'm really interested to hear your ideas on that:

#### **Managing illness and support needs**

I'd like to talk about your health condition. Are you ok to continue?

5. How did you find out about your condition?
6. Can you tell me about how you've been managing with your condition?

7. Has anything more been explained to you about your condition since first diagnosis?  
How did you feel about that? What were your concerns?
8. What kind of medical care have you had since receiving your diagnosis?
9. What care have family / friends been able to give you?

#### **Experience of support from substance use / end of life services**

10. Since your diagnosis, have you had any thoughts about different kinds of support/service you might find useful as your condition changes:
11. Can you tell me about any other services that you've been involved with since your diagnosis?
12. How comfortable are you in talking to staff in these services about your drug/alcohol use?
13. Do you have any concerns that your drug/alcohol use might have made any difference in the way in which you have been cared for since your diagnosis?

#### **Improving care and support**

14. How do you feel overall about the support, treatment and care you have received? Are there any ways in which you could be better supported?
15. Do you have the help you need to manage with your condition?
16. *If appropriate:* Are your family/friends/carers supported enough to feel confident in caring for you?
17. Do you have any thoughts on what you might say to others in a similar situation to you?

#### **Final question**

18. Is there anything else you would like to tell me that we haven't covered in our conversation today?

Thank you

[Provide info sheet about sources of support. Is someone with you?]

## Appendix 2: Combined and final coding frame

Table 4: Descriptive codes, interpretative codes and central themes

Black text: codes created by both researchers independently.

Red text: mixture of codes created by both researchers, subsequently agreed as valid and necessary.

Descriptive codes	Interpretative codes	Central themes
<p>Abuse in relationship Poor parenting Neglect Lack of connections (interpretative) Childhood Historic trauma or abuse experiences Others witnessing substance use problems Perceived cause of substance misuse</p> <p>Stereotyped Can't escape the past Just seen as alcoholic Having to work hard – not to scare health professionals/ to gain trust Shame/guilt Being shamed Historic feelings of guilt Impact of user identity Self-identity and others perceptions Stigma</p> <p>Alcohol as comforter/Pain relief/Mask Brought up in drug culture Self-inflicted Antecedent health problems Development of substance problem Harm to family life from substance use Harm to health from substance use</p>	<ul style="list-style-type: none"> <li>Childhood background</li> <li>Carrying SU Identity</li> <li>Substance use development</li> </ul>	<p><b>THEME 1:</b> Anticipation of discrimination</p>
<p>Told to stop smoking – by professionals Ignored warning signs Conscious 'self-warnings' – reflections Not wanting to stop Current health problems Experience of detox and rehab Warnings about health risk</p> <p>Abstinent at late stages of illness (hope?)</p>	<ul style="list-style-type: none"> <li>Previous warning signs/messages around substance misuse and behaviour change</li> </ul>	<p><b>THEME 2:</b> Understanding the substance use and end of life nexus</p>

<p>Hope?</p> <p>Not been able to use due to illness</p> <p>Avoiding risks to health</p> <p>Barriers to ceasing problematic use</p> <p>Controlling substance use</p> <p>Motivation for ceasing substance use</p> <p>Resisting prescribed drugs</p> <p>Self-awareness of substance use problem</p> <p>Support to stop using substances</p>	<ul style="list-style-type: none"> <li>Substance misuse – direct behaviour change</li> </ul>	
<p>Self-diagnosis</p> <p>Dr diagnosis</p> <p>No diagnosis</p> <p>Shocking/surprising diagnosis</p> <p>Who is in place/position to diagnose/tell</p>	<ul style="list-style-type: none"> <li>Diagnosis experiences</li> </ul>	<p><b>THEME 3:</b> End of life care communication</p>
<p>Worrying about having to ‘tell’ family of illness</p> <p>Worrying about specific family members</p> <p>Needing help/guidance on how to tell family/children</p> <p>Concern for others</p> <p>Family attitude to EOL</p> <p>Family awareness of substance misuse problem</p> <p>No-one actually told me</p> <p>Not admitting</p> <p>Feelings towards EOL diagnosis</p> <p>Realising EOL approaching</p> <p>Worried about pain?</p> <p>Not worried</p> <p>Planning for death</p> <p>Adjusting to EOL</p> <p>Anxiety</p> <p>Dying in poverty</p> <p>Thoughts about dying</p> <p>At home</p> <p>Not alone</p> <p>Not in hospital</p> <p>Planning around death</p> <p>Current personal relationships</p> <p>Fragmented family relationships</p>	<ul style="list-style-type: none"> <li>Managing family members/telling family and friends</li> <li>Articulation of realisation of end of life</li> <li>Concerns/conflicts around accepting death/dying</li> <li>Preferred place of death</li> <li>Current personal relationships</li> </ul>	<p><b>THEME 4:</b> Adjusting to end of life and end of life care needs</p>
<p>Non-existent</p> <p>Hospital – just a number</p> <p>Horrible experience with Drs/consultants</p>	<ul style="list-style-type: none"> <li>Relationships with services</li> </ul>	

<p>Lovely/brilliant in hospice setting  Confusion around relationship (maintaining autonomy, yet needing help/ conflicts)  Accessing services  Social isolation  Substance misuse services</p> <p>Pain  Prescribing</p> <p>Quest for knowledge  Knowledge is power  Maintaining independence – hope?  Maintaining independence</p> <p>Space and time important (hospital/hospice/ stage of illness)  Practical support  Humanistic support  Undeserving support  Current living arrangements  Hospice</p> <p>All older people in a hospice  Better when people are a similar age  Current need for support  Social isolation  Talking to others about EOL</p> <p>Disjointed  Confusing/ difficult in practical terms (appointments etc.)  Perceived lack of care  Accessing services  Experience of hospital  Future care and treatment  GPs and primary care  HP communicating EOL – lack of  HPSC advice re substance use  Interaction with HSC services  Limitations in informal support for PWE at EOL  Macmillan and cancer support  Negative HSPC attitudes  Poor HSPC care  Segmented treatment</p>	<ul style="list-style-type: none"> <li>• Managing pain / pain relief</li> <li>• Control / ownership / expertise</li> <li>• Support/caring</li> <li>• Belonging – the need to be with similar people</li> <li>• Treatment/care experiences</li> </ul>	<p><b>THEME 5:</b>  Managing the treatment and care experience: the need for helpful, holistic and humanised care</p>
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## Appendix 3: Additional case study

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### *Example of PWE dropping out of substance use treatment due to physical ill-health*

Debbie has COPD and currently needs 24/7 oxygen therapy and almost permanent bedrest.

She had been in drug treatment (along with her partner), receiving opiate substitute therapy for many years. She was also smoking one bag of heroin daily which gave her some respite from breathing difficulties for an hour or so. But the changing treatment ethos resulted in her being required to attend key appointments, participate in group-work and give clean urines – or else she was told she would undergo a ‘therapeutic detox’ and be discharged.

Debbie was unable to comply and so has been taken off her prescription. Her partner now gives her half of his script and shoplifts to buy heroin. They are currently using about four bags a day.

Her primary care input is basic: she gets medication delivered and her GP calls out to see her when necessary. District nurses visit but are perceived to give her a ‘wide berth’ because she can come across as angry and unpredictable. Debbie had ceased smoking tobacco but has recently started again because of stress.